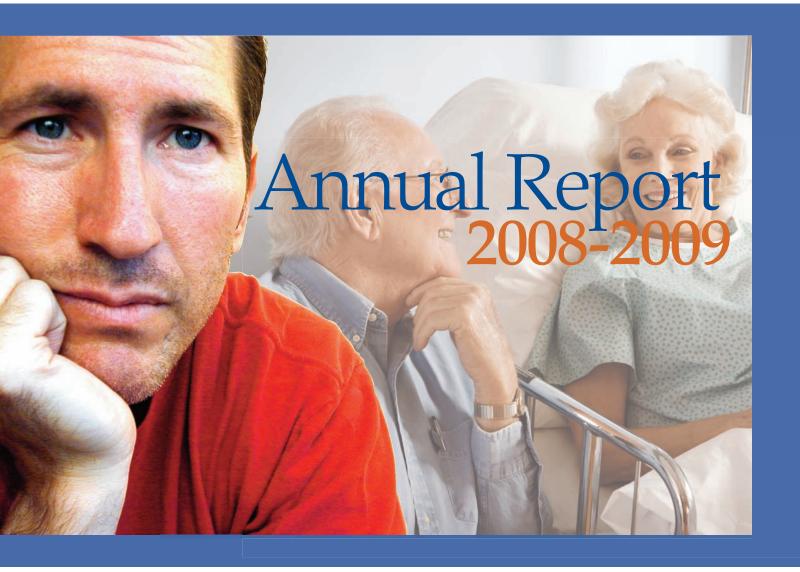
# Patient Advocate Foundation



SAFEGUARDING

PATIENTS

THROUGH

**EFFECTIVE** 

**MEDIATION** 











ASSUDING

ACCESS TO CARE,

MAINTENANCE

OF EMPLOYMENT











**PRESERVATION** 

OF THEIR

FINANCIAL STABILITY

RELATIVE

TO THEIR









Patient Advocate Foundation

Solving Insurance and Healthcare Access Problems | since 1996

DIAGNOSIS

OF LIFE

E '

THREATENING

OR

DEBILITATING

DISEASES



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# Strength

# A WORD FROM THE CEO



# Complex Access Issues Drive Larger Gaps

As I reflect on FY2008-2009, a year of such national financial tragedy for so many Americans, thank you is the first thought that comes to mind ...

Thank you to the 48,127 patients and their loved ones who trusted our team of professionals to find solutions to the often life threatening problems they were facing.

Thank you to our state and federal government sponsored assistance programs and the officials who administer them, as well as, our non-profit and industry partners who continue to recognize that their support is providing real answers to real problems that threaten the health and financial well-being of real patients and their families. PAF saw a 13.45% increase in the number of insurance resolutions achieved for the 58.85% of the patients confronting insurance denials.

Thank you is so appropriate for our many very special non-profit patient advocacy partners, not only those who refer their patients to us, but also those who financially underwrite our services including Susan G. Komen for the Cure, the Lance Armstrong Foundation, and the American Cancer Society. These partners share our passion to provide patients access to prescribed healthcare while appreciating the power and impact meaningful collaborations make for those we jointly serve.

In FY2008-2009, our professional case managers, call counselors, and organizational support teams increased our service to America through our regional and national outreach programs, achieving a 347% increase in service to live chat users, 40% of whom were health care professionals. Case managers made 560,464 calls to insurers, employers, government agencies and other pertinent stakeholders on behalf of our patients to achieve resolution to their access problems. Our team was successful in negotiating \$12,081,891 in medical debt relief on behalf of our patients through write offs, charity care and coding and billing error resolutions. To further educate and support patients and caregivers, PAF delivered 130,672 pieces of educational materials to patients that included information about their disease, medication access options, state and federal government sponsored assistance programs as well as patient advocacy programs that could lend assistance to their issues. Each service sought to simplify complex issues.

Thank you to every donor, member of our Boards of Directors: Executive, Scientific, and Honorary, for and to the PAF Executive Roundtable and Leadership Team members all who contributed to a 11% increase in revenues over projected revenues for this fiscal year, allowing us to broaden our services further. Gratitude is an emotion felt by each patient served and each of us who served them. It is our hope that as you read our Annual Report, you will feel gratitude from us for your role in drafting the successes recorded herein that changed lives forever.

Nancy Davenport-Ennis Chief Executive Officer

# FY2008-2009 Points of Impact

48,127	Patients provided direct, sustained assistance from the PAF professional staff
560,464	Contacts made by PAF staff on behalf of patients to relevant stakeholders in order to bring resolution to health care access issues
\$12,081,891	Value of debt relief obtained for PAF patients through negotiated write offs, charity care access and coding/billing error resolutions
25,123	Number of patients served through the PAF Co-Pay Relief Program since its inception
\$50,000,000	Amount surpassed this year for cash assistance provided through the PAF Co-Pay Relief Program
130,672	Pieces of educational materials distributed to patients, caregivers and health care professionals
29%	Growth in unique visitors to PAF web sites this year
2,437,647	Pages viewed this year by PAF website visitors
367%	Growth in online patient chats facilitated by PAF professional staff
1	Organization, making an impact

# A WORD FROM THE BOARD PRESIDENT



As we look to the future of healthcare in this country and the extraordinary efforts underway in Washington, D.C., to bring change, Patient Advocate Foundation remains committed to its core mission of safeguarding patients in need. PAF continues to assert itself as a leader among advocacy organizations by championing access to quality healthcare and preserving financial stability among patients who face serious or life-threatening diseases.

Look at our accomplishments this year. More than 48,000 patients have secured direct, sustained assistance from the professional staff at PAF. More than 560,000 contacts have been made by PAF staff on behalf of

patients to relevant stakeholders in order to bring resolution to healthcare access issues. Staff have worked tirelessly on behalf of patients to obtain relief through negotiated write offs, charity care access, and coding/billing error resolutions. The value of debt relief obtained by PAF patients tops a staggering \$12 million. Since inception, the PAF Co-Pay Relief Program has served more than 25,000 patients and provided more than \$50 million dollars in cash assistance.

PAF has provided patients in need with up-to-date print and online information on such varied issues as clinical trials, insurance, and senior services. More than 130,000 brochures, reports, and other educational materials have been distributed to patients, caregivers, and healthcare professionals. Online, we have seen a 29 percent increase in unique visitors to PAF websites this year, with almost 2.5 million pages viewed. Online patient chats facilitated by PAF staff have seen a 367 percent jump.

All of this, of course, could never happen without the dedication and hard work of PAF staff. I want to thank each of them for their enthusiasm and support.

Patient Advocate Foundation is known as a leader among advocacy organizations and has gained that reputation through constant, committed, and personal service. Each day patients reach out to Patient Advocate Foundation. And each day in response, the PAF family offers a lifeline of guidance, kind words, and assistance.

On behalf of the Board of Directors of Patient Advocate Foundation, we thank the leadership, staff, patients, and supporters for their commitment and an extraordinary year well done.

Christian Downs President, Board of Directors

# BOARD OF DIRECTORS

## **Executive Board Members**

Nancy Davenport-Ennis, Founder

CEO, President

Patient Advocate Foundation &

National Patient Advocate Foundation

Christian Downs, MHA, JD, President

**Executive Director** 

Association of Community Cancer Centers

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Associate Administrator for HIV/AIDS

Health Resources and Services Administration

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President, Clinical Services and Chief Medical Officer

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**John H. Ennis**, Co-Founder

Chief Development Officer

Patient Advocate Foundation

non-voting member

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Director, Cellular Therapeutics

Rocky Mountain Blood and Marrow

Transplant Program

Rocky Mountain Cancer Centers

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University of Washington

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Professor of Radiation Oncology

Associate Professor of Head & Neck Surgery

Duke University Medical Center

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Lori Williams, Ph.D., RN, AOCN

University of Texas

MD Anderson Cancer Center

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Oncology Nursing Society

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Administrative Officer

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**Doris Simonson** 

Mother of Cheryl Grimmel

Sheldon Weinhaus, Esquire

Weinhaus and Postashnick

# NOTEWORTHY NEWS



## VIRGINIA GENERAL ASSEMBLY PROCLAMATION

On February 28, 2009, during Patient Advocate Foundation's annual *A Promise of Hope Affair*, a proclamation from the Virginia General Assembly was presented to Nancy Davenport-Ennis and Jack Ennis. House Joint Resolution No. 771, which was approved by the Virginia House of Delegates with the Virginia Senate concurring, designates every April 4<sup>th</sup>, the founding date of Patient Advocate Foundation, as Patient Advocate Day in Virginia.

## Prostate Net Award

PAF was recognized by Prostate Net with an "In The Know" award for 2008. These awards are designed to honor those who have gone beyond the routine to change the paradigm of negative impact on medically underserved communities. Because of PAF's two disparate outreach programs, the National African American Outreach Program and the National Hispanic/Latino Outreach Program, as well as our work on the CDC cooperative agreement on the Early Detection and Survivorship of Cancer in Underserved Populations (SCUP), Patient Advocate Foundation was recognized as the Patient Services organization for 2008.

Founded by Amgen in 2005 as a complementary component to the company's sponsorship of the Amgen Tour of California, Breakaway from Cancer<sup>TM</sup> strives to raise awareness of the important resources available to cancer patients from prevention to education and patient advocacy and financial support. The initiative includes charitable partners National Coalition for Cancer Survivorship, Prevent Cancer Foundation, The Wellness Community, Stand Up To Cancer and Patient Advocate Foundation.

Breakaway from Cancer<sup>TM</sup> nonprofit partners play leading roles in every aspect of cancer care to help people affected by the disease. The Escondido Breakaway Mile highlighted Patient Advocate Foundation. "Breakaway from Cancer<sup>TM</sup> is an initiative that captures the essence of every cancer patient's commitment as they face their fears and race to conquer cancer," said Nancy Davenport-Ennis, PAF founder and CEO. "We are so very honored to be a partner in this event with our fellow nonprofit colleagues and to join the survivors and their caregivers in celebrating with professional cyclists the thrill of victory as their ride calls out the importance of cancer research and survivorship for all patients and their loved ones in the United States."

"Amgen is proud of our sponsorship of the Amgen Tour of California, a spectacular race that again this year saw the world's best cyclists battle it out along California's beautiful landscape," said Joe Miletich, Senior Vice President of Research and Development at Amgen. In addition to riding in the Breakaway Mile, Miletich also presented the final Amgen Leader Jersey to 2009 Amgen Tour of California winner Levi Leipheimer. "As a company dedicated to tapping the power of pioneering science to fight serious illness, Amgen is passionate about helping people who are battling cancer, and Breakaway from Cancer™ is one of the ways that Amgen is fighting cancer on multiple fronts. The 17,000 staff members at Amgen come to work every day motivated by the chance to make a dramatic difference in the lives of people suffering from cancer and other life threatening illnesses."



Faith

# DIRECT PATIENT SERVICES DIVISION

## FY2008/2009 DIRECT PATIENT SERVICES DIVISION SUMMARY

## **Summary of Patient Cases and Contacts**

j	
New Case Count	32,227
Re-Opened Case Count	1,200
Total Email Contacts for Direct Patient Services	14,700
<b>Total Patient Case Count</b>	48,127
<b>Total Contacts for Case Resolution</b>	560,464

For over 13 years, Patient Advocate Foundation has had the privilege of helping patients solve their insurance and healthcare access problems through our Direct Patient Services Division that includes the professional case management staff, the Co-Pay Relief (CPR) staff and the Med CareLine staff. Case Management and Co-Pay Relief remain PAF's core competencies, with case management being the founding core competency for PAF. From serving 157 patients in 1996 to serving 48,127 patients in FY2008/2009, Patient Advocate Foundation has remained true to its mission of safeguarding patients and eliminating barriers to healthcare access.

The Direct Patient Services Division generated 560,464 contacts on behalf of patients to bring resolution to their access issues. This averages 16.76 contacts from a PAF professional case manager and/or Co-Pay Relief specialist to a relevant stakeholder in the patient case, including, but not limited to, the patients healthcare providers, social workers at governmental agencies, employer representatives, creditors and/or other representatives from non-profit, social service and healthcare organizations in order to bring resolution to the patient issues for each and every case handled by the Direct Patient Services Division staff. In FY2008/2009 this represents an additional 1.26 contacts per case to bring resolution over FY2007/2008, a clear indication that the complexity of cases continues increase and the available resources continue to decline.

PAF's Direct Services Provided to patients at **no cost** includes:

- Negotiating pre-authorization approvals
- Providing assistance in expediting the appeals process
- Coordinating benefits
- Negotiating resolutions to coding and billing errors
- Providing assistance in expediting applications for SSDI, enrollment in Medicare, Medicaid, SCHIPS, and other social programs
- Resolving debt crisis related to diagnosis
- Mediating insurance appeals
- Negotiating access to pharmaceutical agent, chemotherapy, medical device and surgical procedures
- Brokering resources to supplement the limits of insurance and to assure access to care for uninsured
- Resolving insurance issues in the public and private sectors
- Providing co-payment assistance to medically and financially qualified individuals

## Online Patient Services Impact

Every minute of every day a person is visiting a PAF website.

We realize that knowledge is power and time is precious, for all of us.

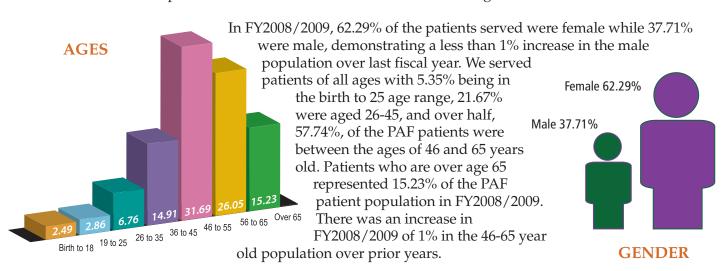
It is with this in mind that Patient Advocate Foundation has utilized highly integrated technology to receive and respond to online requests for assistance, connect patients and healthcare providers to PAF professional case managers instantly via online chats, make available patient resources and educational materials that empower users with the information necessary to overcome patient care obstacles, and facilitate webinars designed to educate on PAF services as an adjunct to our targeted outreach programs. PAF websites have proven to be a valuable resource for our visitors, including over 1,800 links from our sites to various educational websites, offering visitors instant access to a wealth of pertinent information. The total visits to PAF sites increased 29% in FY2008/2009 over last year. People visiting the sites viewed a total of 2,437,647 pages during their visits.

In FY2008/2009, PAF outreach teams, including the National Hispanic/Latino Outreach Program, the National African American Outreach Program, the Virginia Cares for the Uninsured Program (VCUP), the Survivorship of Cancer in Underserved Populations (SCUP) program as well as our Co-Pay Relief Program (CPR) hosted over 50 webinars open to both the general public and healthcare professionals, including those working in Public Health positions, designed to educate on the services provided by PAF and how to access them.

Patient Advocate Foundation professional case management team members conducted 845 live chats with patients and/or healthcare providers during FY2008/2009 – a staggering increase of 367% over last fiscal year – providing information, navigation and support in a personalized, instant manner to those using the live chat service.

## PERSONAL IMPACT DEFINED

As PAF works with patients requesting assistance, approximately 220 fields of data are captured on each patient. From this data the *Patient Data Analysis Report (PDAR)* is created on an annual basis to determine what populations are being served by PAF and what patient issues are becoming trends in various regions of the country. Data from the comprehensive *Patient Data Analysis Report* has been mirrored in the context of this FY2008/2009 Annual Report in graphical form in an effort to clearly define who PAF is serving, what the needs of the patients are and what resolutions have been brought to these issues.



# DIRECT PATIENT SERVICES DIVISION

The PAF Senior Services Division, which was created in 2004 in response to the creation of Medicare Part D, continues to provide services to those seniors contacting PAF. Senior Services personnel are asked throughout the year to review coverage and marketing material for Medicare health care plans. Documents are reviewed and comments are submitted. PAF case managers attended the Train the Trainer program with CMS in Boston, MA where CMS representatives gave workshops on coverage topics, web tools and community resources.

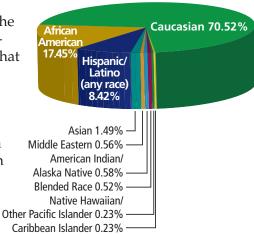
PAF continues to be a part of the Peninsula Task Force on Aging, which serves the Hampton Roads area, participating in the monthly meetings, chairing events such as "Hats off to Caregivers" which honored medical personnel caring for our seniors and disabled, serving on a Task Force outreach team and being listed through the Task Force as a resource for Medicare Part D issues at local pharmacies.

The Senior Services team participated in the Portsmouth, VA Senior Health Fair, the Newport News, VA Healthy Lifestyles Program and the Newport News Senior Fair, The Virginia Oncology Associates Community Day as well as the Area Agency on Aging workshop for Medicare prescription coverage education and guidance to our community. PAF also attended the World Group Clinical Documentation Expo in Chicago, IL where many specialty cancer treatment hospitals such as Sloan-Kettering and Loma Linda University came together to discuss medical documentation and idea's to better service the patient in their insurance billing needs.

PAF assisted patients of many ethnicities with 70.52% of patients classifying themselves as white/Caucasian, 17.45% considered themselves black or African American and 8.42% were

Hispanic/Latino. We saw a 0.68% decrease and 0.38% increase in the White/Caucasian and Black/African American populations respectively this year over last, while seeing a decrease in the Hispanic/Latino population of 0.20%. The racial demographics of the PAF patient population are largely consistent with the statistics presented in the Census Bureau's 2008 American Community Survey that reported the US Population as being 65.4% White American, 15.4% Hispanic or Latino of any race, 12.1% Black American, 4.4% Asian American, 0.7% American Indian and Alaska Native, 0.1% Native Hawaiian or other Pacific Islander, 0.2% some other race and 1.7% two or more races. PAF has two well established disparate outreach programs that are effective in offering culturally sensitive education and direct assistance to patients from both the Spanish speaking communities and the African American community.

## **ETHNICITY**



## The National Hispanic/Latino Outreach Program (NHLOP)

seeks to improve access to health care for the chronically and critically ill patients from Spanish speaking communities by promoting the services of PAF to those in the Hispanic and Latino communities. PAF has bilingual case managers in New York and California who dedicate 8 hours per week to providing outreach and education in specified Hipanic/Latino communities. These case managers are also tasked with translating every PAF authored publication into Spanish and updating them on an ongoing basis to suit the needs of the population.

This year the PAF Spanish website was redesigned and is continually updated, including for example the Spanish announcement of the *Social Security Administrations Compassionate Allowance*, which allows many of our Spanish webpage viewers to be informed about this new measure to expedite Social Security claims for those with specific cancers. The *Blood Cancer Resources* Spanish webpage has been completed for those with in the Hispanic/Latino communities facing issues with blood cancers.

A PAF bilingual case manager was featured in a live radio show, "Comentando" 1350AM, that broadcasts to Spanish speaking listeners in the states of Virginia, New Jersey, Maryland and Pennsylvania. Topics covered included issues in the Hispanic/Latino community relative to cancer or other life threatening, debilitating illness and how to manage financial difficulties and issues pertaining to clinical trials and insurance matters. PAF also serves on the Lance Armstrong Foundation's Spanish Advisory Committee to assist with the development of the LIVESTRONG Cancer Survivorship National Hispanic Media Campaign.



Beverly McNearly-DeRavailliere, Co-Pay Relief Assistant Directro shares information about the various diseases served by the PAF CPR Program.

In August of 2008, a PAF patient who is Spanish speaking, was featured in the August edition of "Latina Magazine", which is circulated primarily in metropolitan areas of the United States within the Hispanic/Latino communities that described her experience with PAF and the resolution of her issues relative to her diagnosis. The Director of NHLOP was invited to serve on the Eliminating Disparities in Clinical Trials – EDICT Project round table committee to discuss issues and solutions to the lack of participants from the Hispanic/Latino population in clinical trials. The issues and suggestions discussed have been published in their latest Policy and Recommendation booklet.



**Beatrice G**Kidney Disease
New York, NY

"If it was not for your help, I couldn't have made it paying for my medications. Your company is a Blessing!!!"

The NHLOP also created an educational webinar program that is conducted on a monthly basis to educate medical professionals, social workers and other case managers who assist patients in the Hispanic/Latino community. Additionally, NHLOP case managers participated in 41 outreach events including the National Council of La Raza, National Hispanic Medical Association 13<sup>th</sup> Annual United Nations Reception, Asian American Women's Health Symposium and the Reunion Latina.

staff participated in 29 local, regional and national outreach events, educating over 21,000 individuals about PAF and the services provided to patients within the African American community. These events included the NAACP 99<sup>th</sup> Annual Convention, the National Black Nurses Association Annual Conference, the Annual Health Disparities Conference, the National Association of Black Social Workers Conference and the Howard University Conference. NAAOP continues to collaborate locally with the South East Community Health Task Force in Newport News, VA and other local

The National African American Outreach Program (NAAOP)

When NAAOP was launched in 2004, over 13% of the patients served by PAF were African American. The percentage of African Americans provided the comprehensive case management services in FY2008/2009 increased to 17.45%.

organizations to empower and educate local residents about

In 2008, PAF completed the final year of a five year cooperative agreement, the **Early Detection and Survivorship of Cancer in the Underserved Populations (SCUP)** with the Centers for Disease Control. PAF submitted an application under competitive bid and was awarded a second five year cooperative agreement on September 1, 2008. The goals of SCUP are to increase survivorship of cancer and enhance quality of life by providing direct case management services for patients with breast, cervical, colorectal,

chronic diseases.

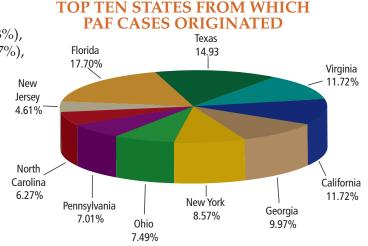
# DIRECT PATIENT SERVICES DIVISION

prostate, ovarian and skin cancers in underserved populations. PAF provides outreach and education to increase awareness of our services available to the uninsured, underinsured, minority and disparate populations.

In FY2008/2009 PAF served 3,953 patients through SCUP with specific needs in accessing healthcare and medications, resolving debt crisis issues and assisting patients in applying for public benefits. 1,441 patients were provided information about clinical trial opportunities for treatment to their disease.

In January, 2009 outreach was conducted in Arizona to the Arizona Cancer Center, the Mayo Clinic, Virginia G. Piper Cancer Center and St. Joseph Hospital and in Nevada to the Nevada Health Board Office, Bureau of Healthcare and Compliance and the University Medical Center of Southern Nevada. Our SCUP team members also met with the CDC Comprehensive Cancer Control Directors in both states. Members of NHLOP and NAAOP also participate in outreach events to reach the target populations and inform them of SCUP services.

The top ten states that the patients came from in FY2008/2009 were Florida (17.70%), Texas (14.93%), Virginia (11.72%), California (11.72%), Georgia (9.97%), New York (8.57%), Ohio (7.49%), Pennsylvania (7.01%), North Carolina (6.27%) and New Jersey (4.61%). When comparing the states from which the patient cases originated to the states, based on population density, that top the United States Census Bureau's July 1, 2008 estimates, all ten states listed above are among the top twelve (12) states, by population. During FY2008/2009, Florida and Texas remained the top states of residence for PAF patients, with Virginia ranking third. By contrast, Virginia is ranked 12<sup>th</sup> in population per the US Census Bureau.



Patients find their way to PAF in a multitude of ways as PAF has become a reliable referral source for non-profit, social service and healthcare organizations, governmental agencies, including the field and national offices of members of the United States Congress, providers' offices, clinics, hospitals and media outlets. In FY2008/2009 referrals from American Cancer Society represented 41.69% of patients being served by PAF and Lance Armstrong Foundation (LAF) referrals represented 9.79% of the PAF patient population.

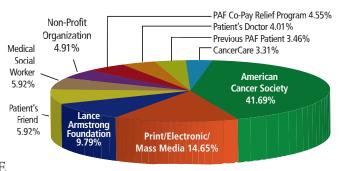
American Cancer Society®

In FY2008/2009 Patient Advocate Foundation completed it first year of its partnership with the **American Cancer Society.** The goal of the partnership is to ensure that cancer patients are able to access affordable care and pharmaceuticals and are provided case management services to resolve their insurance and job retention issues related to their diagnosis. "There are entirely too many patients and family members struggling with rejected claims, denials based on pre-existing conditions and additional insurance coverage challenges that

can lead to life-or-death delays in treatment," said Nancy Davenport-Ennis, CEO of PAF on the launch of the partnership program. "Together, the American Cancer Society and Patient Advocate Foundation are committed to providing the help that cancer patients need and fighting on behalf to help eliminate these barriers."

During FY2008/2009 PAF provided direct case management services to 5,591 patients through the ACS/PAF Partnership program. These referrals were received via telephone or through a secure web-based ACS patient referral portal. The portal accounted for about 25% of cases referred during the year. Patients who were referred by ACS who would be better served though other PAF programs such as the two CDC Cooperative Agreement programs (SCUP and HemOnc), or the Colorectal CareLine, were referred to those programs and accounted for an additional 2,225 patients who were referred by ACS to PAF.

## **TOP TEN REFERRAL SOURCES**



Patricia M., from Hawthorne, FL best sums up the services provided through this partnership: "Thanks to my PAF patient navigator case manager! She has handled my claim with all needed information and speed and helped me communicate with the hospital. She also told me about Co-Pay Relief for my medicines. She is the ONLY one who gave me 100% help".

## LIVESTRONG

PAF celebrated its fifth year of partnership with the Lance Armstrong Foundation (LAF) and the LIVE**STRONG** Survivor*Care* program in FY2008/2009. There have been numerous new

marketing efforts and initiatives this year and it is anticipated that national marketing of the LIVE**STRONG** Survivor*Care* project will remain a high priority continuing in the FY2009/2010. Highlights for FY2008/2009 include:

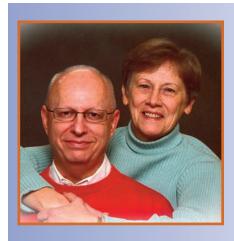
- The LIVE**STRONG** Survivor*Care* website was revised to highlight the services available to cancer survivors.
- The LAF developed a new LIVE**STRONG** Survivor*Care* brochure and LIVE**STRONG** Guidebook Notebook to now include services available in Spanish.
- PAF presented a webinar to the LAF and LIVE**STRONG** Survivor*Care* partners, highlighting PAF services.
- PAF continues to sit on the LIVE**STRONG** Survivor*Care* National Hispanic Outreach Advisory Board to assist with all aspects of the LIVE**STRONG** Survivor*Care* National Hispanic/Latino initiative.
- LIVE**STRONG** Survivor*Care* partners have started to conduct bi-weekly case conference calls to provide more services to patients contacting LIVE**STRONG** Survivor*Care* for assistance.
- Welcome packets consist of a welcome letter, LIVE**STRONG** Survivor*Care* brochure and LIVE**STRONG** Survivor*Care* magnet.
- 3 month follow-up surveys continue to be sent to each patient that contacts LIVE**STRONG** Survivor*Care*. Results are shared with partners monthly.

Through this increased marketing, PAF provided assistance to 1,797 referrals in FY2008/2009. Since inception of the LIVE**STRONG** Survivor*Care* partnership, PAF has assisted 7,944 patients. One patient assisted by the LIVE**STRONG** Survivor*Care* program states:

"As you know, metastatic carcinoma stage IV can be an overwhelming diagnosis-after our insurance lapsed-we did not know what we were going to do. I contacted LAF via e-mail and received an immediate response from a PAF case manager. She was truly a blessing for my husband. She contacted the hospital, contacted SSI and Needymeds. The hospital has a charity program so Dale can receive treatment. She contacted SSI for us and this looks like Dale will receive disability. We truly are so very thankful for your organization and most of all our case manager."

-Wife of Dale Biechler, Illinois

# DIRECT PATIENT SERVICES DIVISION



Candace P Lupus Harleysville, PA

"I am writing to PAF to say thank you for helping me to get a refund due my wife. I had paid and so had my wife's health insurance company. Without PAF's assistance, I would not be getting the \$830 returned. Thank you so much PAF, Blessings to PAF for your concern and loving care."

In FY2008/2009, PAF was featured by over 20 tier one media outlets, including: Associated Press, CNN, MSNBC, USA Today, The Washington Post, Market Watch, Essence, AARP, Los Angeles Times, The Atlanta Journal-Constitution, The Washington Post, Chicago Tribune, Consumer Reports and The Wall Street Journal.

Additionally, PAF was featured in tier two media outlets and websites, magazines, trade publications and television. As a result, in FY2008/2009, earned media coverage is the third highest referral source, of patients seeking assistance with 14.65% of all patient referrals generated from earned media coverage. Additionally, referrals from patient's friends, doctors, medical social workers, CancerCare, many other Patient Advocacy Organizations, PAF's Co-Pay Relief Program and patients previously served by PAF round out the top ten referral sources for FY2008/2009.



Allison H
Breast Cancer
Shaker Heights, OH

"PAF case manager provided resources in the patients county that offers assistance with rent/mortgage essential utility bills, medical insurance premiums, prescription expenses, medical supplies, automobile expense and day to day financial burdens; even daycare!"









The Washington Post



ESSENCE.com
ESSENCE



## Ios Angeles Times

TheAtlanta Journal-Constitution

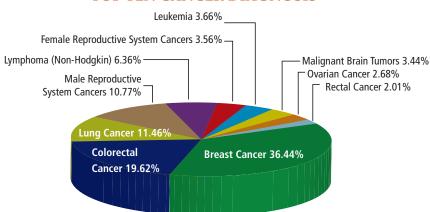
The Washington Post





THE WALL STREET JOURNAL

## **TOP TEN CANCER DIAGNOSIS**



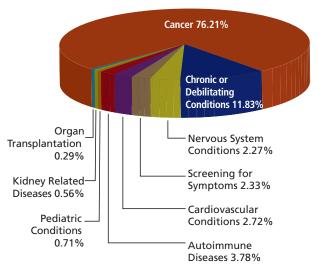
Female Reproductive System Cancers Include: Fallopian Tube Cancer **Uterine Cancer Cervical Cancer Vaginal Cancer Ovarian Cancer Vulva Cancer** Padgett's Disease

Male Reproductive System Cancers Include: **Prostate Cancer Penile Cancer Testicular Cancer** 

Cancer continues to be the primary diagnosis of PAF patients with 76.21% of all patients served reporting a diagnosis of cancer, representing a 1.62% increase from FY2007/2008. Breast Cancer (36.44%) was the leading cancer diagnosis among our patients again this year with Colorectal Cancer quickly following at 19.62%, a 0.61% increase from last year. Lung Cancer diagnosis represented 11.46% of our patients, while Male Reproductive System Cancers were at 10.77%, representing a 2% increase over last year. Diagnoses of Lymphoma (6.37%), Leukemia (3.66%), Female Reproductive Cancers (3.56%), Malignant Brain Tumors (3.44%), Ovarian Cancer (2.68%) and Rectal Cancer (2.01%) were all included in the top ten cancer diagnoses of PAF patients.

While cancer is the number one diagnosis of PAF patients, PAF has provided direct patient support to people who have been diagnosed with various chronic, life threatening and/or debilitating illnesses. The remainder of the top ten diagnoses of PAF patients for FY2008/2009 includes Chronic/Debilitating Conditions (11.83%), of which there are over 100, Autoimmune Diseases (3.78%), a 1.44% increase over last year, Cardiovascular Conditions (2.72%), Screening for Symptoms (2.33%), Nervous System Conditions (2.27%), Pediatric Conditions (0.71%), Kidney Related Diseases (0.56%) and Organ Transplantation (.029%).

## TOP DIAGNOSIS OF PAF PATIENTS



### Adrenal insufficiency Fasciitis Fibromatosis Amyotrophic Lateral Sclerosis (ALS) Fibromvalgia Amputation (any limb) Amyloidosis Glaucoma Hidradenitis Anemia Hemophilia Aplastic Anemia Asthma Hepatitis Blindness Histoplasmosis **Bronchitis** Histiocytosis Cirrhosis HIV/AIDS Clotting disorder Connective tissue disease Chronic Obstructive Pulmonary disease (COPD) Hypopituitarism Cushing's syndrome Degenerative disc disease Degenerative joint disease Devic's disease or Neuromyelitis optica Liver failure Diabetes Lymphedema Leukodystrophy Encephalopathy Enzyme deficiency Malabsorption

CHRONIC OR DEBILITATING CONDITIONS Neuropathy Neutropenia Osteomyelitis Gaucher's disease Osteonecrosis Osteoporosis Pancreatitis Paralysis (any body part) Parathyroid disorders Polio Polycythemia vera Protein deficiency Hunter's syndrome Pseudomyxoma Peritonei Hyper/Hypo Thyroidism (PMP) Pulmonary emboli Huntington's disease Hypogammaglobulinemia Pulmonary fibrosis Pseudoxanthoma Elasticum Immune Deficiency disorder (PXE) Short Bowel syndrome Infectious diseases Idiopathic thrombocy Sickle Cell Anemia topenic purpura (ITP) Thrombocytopenia Thyroid disorder Thrombotic thrombocy topenic purpura (TTP) Macular Degeneration Tuberculosis Turner syndrome Monoclonal gammopathy **Ulcerative Colitis** Myelofibrosis Muscular Dystrophy

polyposis (FAP)

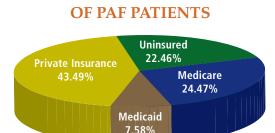
# DIRECT PATIENT SERVICES DIVISION

In FY2008/2009, PAF completed the second year of a second five year cooperative agreement from the Department of Health and Human Services Centers for Disease Control and Prevention (CDC). The **Hematologic Cancer Education and Outreach Program (HemOnc)** is designed to assist in determining the effectiveness of current educational materials available for hematologic cancer patients, with a focus on individuals who may be underserved, uninsured or racial/ethnic minority, and to identify areas where there may be opportunities to collaborate with other partners to improve future publications. *Lighting the Way: A Practical Guide to Clinical Trials*, was published in May 2009 to fill a need that was identified through patient interactions. This publication focuses on dispelling clinical trial myths and offers practical information on researching clinical trials and guidance on overcoming access barriers within the minority communities. It is being developed into one of PAF's "A Greater Understanding..." series of brochures as well.

During FY2008/2009 PAF served a total of 1,281 blood cancer patients with an average of 320 patients served quarterly. This project includes a disparities outreach component, targeting African American and Hispanic/Latino hematologic cancer patients, and the organizations and healthcare facilities that serve those populations. States visited during the fiscal year include:



During outreach swings to a particular state, major research hospitals are visited to educate them on PAF services, particularly on services to hematologic cancer patients. In addition, outreach is also conducted to smaller regional hospitals, clinics, community health centers and physician practices to educate them as well. HemOnc staffed attended The Association of Pediatric Oncology/Hematology Nurses (APOHN) Conference, The National Comprehensive Cancer Network (NCCN) Annual Conference, Oncology Nursing Society (ONS) Conference, Association of Oncology Social Workers Conference and the American Society of Pediatric Hem/Onc (ASPHO) Conference.



**INSURANCE STATUS** 



Of the patients served in FY2008/2009, 77.54% had some form of insurance. It was reported that 43.49% of the patients served by PAF were privately insured, 7.58% were receiving Medicaid and 24.47% were covered under Medicare. This data represents a 3.93% increase in the Medicare patients and a 2.10% decrease in Medicaid patients served this fiscal year versus last. As well, 22.46% of all PAF patients in FY2008/2009 reported being completely uninsured for their healthcare needs.

The number of uninsured patients being served by PAF is due, in part, to our administration of **The Virginia Cares Uninsured Program (VCUP)** that was implemented in 2007 to assist uninsured Virginians who have been diagnosed with a chronic, debilitating, and/or life threatening disease and are experiencing issues

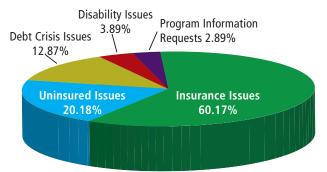
accessing health care. Part of assisting Virginians with accessing health care involves resolving debt crisis issues to include medical debt. For FY2008/2009 VCUP assisted patients with obtaining a reduction on their medical debt in the amount of \$263,836.80, whether through charity assistance provided by the medical facility or negotiating a write-off.

One of the patients assisted by VCUP was a 48 year-old African American female who was diagnosed with multiple illnesses to include diabetes, asthma, diverticulitis, and carpal tunnel syndrome. She contacted PAF requesting assistance with her unpaid medical debt and accessing care. The VCUP case manager was able to facilitate access and approval for charity care through the medical facility and the patient's entire balance of \$45,201.23 was written off. The VCUP case manager was also able to set up an appointment with a specialty provider that billed the patient's medical care on a sliding scale. Another patient in Alexandria, VA writes: "The Foundation helped me get low cost medical care, which I so desperately needed."

In addition, VCUP has an outreach component to ensure that Virginians who may be experiencing obstacles accessing health care are educated on our services. For FY2008/2009 VCUP conducted outreach at health fairs, free clinics, community health centers, social service departments & hospitals in over 200 cities and counties across the Commonwealth of Virginia. Some of the conferences attended include the Annual Session of the Baptist General Convention, the Remote Area Medical Health Expedition, the 2<sup>nd</sup> Annual Ability Awareness Day, the Virginia Association of Free Clinics Annual Meeting, Virginia Community Healthcare Association Annual Leadership Conference and the Cover the Uninsured Week Resource Fair.

Patients that contact PAF for assistance have a wide variety of needs and are offered services that have breadth and depth that are currently unmatched. In FY2008/2009 the top five (5) primary issues patients were seeking assistance with included Insurance Issues (60.17%), a rise of 12.64% from just one year ago, Uninsured Issues (20.18%), Debt Crisis Issues (12.87%), Disability Issues (3.89%) and Program Information Requests (2.89%). PAF continues to be recognized as a leading resource when confronted with access to care issues, this being evidenced by more than 60% of all of the PAF patients requesting assistance with Insurance Issues including co-payment assistance for both privately insured patients and those covered by Medicare Part D, coding and billing errors, alternate healthcare access avenues once benefit maximums have been reached, education around individual and group health insurance benefits, contract language interpretation, appeals assistance, prescription drug and medical service access issues, denial of access to a clinical trial, and assistance with Medicare Part D plan selection and enrollment.

## PRIMARY ISSUES OF PAF PATIENTS



UNINSURED ISSUES INCLUDE:
No access to care
Unpaid medical bills
No access/no coverage for prescription needs
Insurance coverage terminated
No access to screening
Medicaid application assistance needed/expedited
Denied Medicaid access
Denied treatment/inability meet
upfront financial requirement

INSURANCE ISSUES INCLUDE:
Co-pay, premium and/or deductible assistance
Coding and billing errors
Benefit exclusion
Inability to afford Medicare Part D cost share
Exhausted benefit maximum/Annual maximum
General benefit/coverage questions
Contract language/Interpretation
Appeals assistance required
Claims denied due to experimental/investigational

# DIRECT PATIENT SERVICES DIVISION



Phillip C
Colon Cancer
Jackson, MS

"PAF is a very good place to begin a search for valuable help with a variety of issues that are unique to cancer patients." Patient Advocate Foundation has two specialized programs within Direct Patient Services which help to address the needs of those patients reaching out for assistance, the Med CareLine and the Co-Pay Relief (CPR) program.





In November 2006, PAF launched the Colorectal CareLine (CCL), a patient/provider hotline, designed to provide sustained assistance to patients nationwide

who have been diagnosed with colorectal cancer and are seeking educational resources, direct assistance with access to care issues and/or financial aid for select patient needs. The launch of this Med CareLine division was the first time that Patient Advocate Foundation partnered clinical specialists with patients who were seeking access to emerging treatments and therapies.

The Colorectal CareLine continues to administer a small financial grant component for colorectal patients in need of debt crisis assistance for expenses related to out of town care. The CCL Financial Aid Fund currently provides one-time to eligible patients who have a diagnosis of colorectal cancer. FY2008/2009 saw the Colorectal CareLine serving 2,751 patients with case management services and 936 patients were able to utilize the Financial Aid Fund grant.

The Colorectal CareLine staff exhibited and/or presented at the Peninsula Cancer Coalition Meeting, Bureau of Healthcare & Compliance, World Group Clinical Documentation Expo, Oncology Nursing Society (ONS) 34<sup>th</sup> Annual Conference, Virginia Healthcare Association Annual Leadership Conference, the American Society of Clinical Oncology (ASCO) 45<sup>th</sup> annual meeting, and at the Patient Advocate Foundation's 10th Annual Patient Congress held in Washington, D.C. in the Educational Expo for all attendees. The Colorectal CareLine also provided program materials for the Colon Cancer Alliance Quarterly meetings in New York, NY, Santa Monica, CA, Nashville, TN and Tampa, FL.



Michelle Herbert, PAF Case Manager educates a conference attendee on the Colorectal CareLine services

The Colorectal CareLine staff has been successful in bringing medical debt relief in the amount of \$2,647,103.94 to the colorectal cancer patients we have served through CCL since the program launched in November 2006. It is very satisfying to the case managers when they work so diligently with various pharmaceutical companies, hospitals, advocacy groups, insurance companies and state and local agencies and are able to help alleviate some of the debt crisis issues are frequently a companion issue for those dealing with a colorectal cancer diagnosis.



An additional Med CareLine program the Lymphedema CareLine (LCL), launched in November 2008. The Lymphedema CareLine supports patients who are concerned about the risk of developing lymphedema or need assistance with their medical claims relating to the clinical assessment of lymphedema. It also supports providers who are seeking information and/or assistance related to providing and receiving reimbursement for the

clinical assessment and

monitoring of their patients with lymphedema. In FY2008/2009, the Lymphedema CareLine provided assistance to 154 patients/providers.

## PATIENT ADVOCATE FOUNDATION CO-PAY REL EF A Patient Assistance Program

The Patient Advocate Foundation's Co-Pay Relief (CPR) Program has successfully completed 5 years of operation and continues to be one of

the two core competency based programs at PAF. The program was established in April 2004 to provide direct financial support to insured patients, to include Medicare beneficiaries, who qualify medically and financially with their pharmaceutical co-payments.

In the Spring of 2009, PAF's CPR Program profile was included in MattsonJack DaVinci's Oncology Market Access, U.S., Seventh Edition, an annual publication that provides ongoing access to leading-edge analysis of critical shifts in the U.S. marketplace that are likely to impact reimbursement, pricing and utilization of cancer drugs. The analyses presented in the report are based on in-depth qualitative and quantitative market research. In this report, PAF's Co-Pay Relief Program was rated #1 among the charitable co-pay assistance programs by Practice Administrators across the United States for servicing cancer patients.

In FY2008/2009, the CPR program expanded its patient support by opening six new disease funds including:

Hepatitis C

- Multiple Myeloma
- Myelodysplastic Syndrome Rheumatoid Arthritis
- Osteoporosis

■ Chronic Pain

These additions expand our available co-pay support disease categories to 19. Currently the CPR program is assisting patients with the following diagnoses:

- Autoimmune Disorders
- Breast Cancer
- Chronic Pain
- Colon Cancer

Diabetes Hepatitis C ■ Head and Neck Cancer

- Kidney Cancer Lymphoma
- Lung Cancer
- Myelodysplastic Syndrome
- Malignant Brain Tumor Multiple Myeloma
- Osteoporosis
- Pancreatic Cancer
- Prostate Cancer
- Rheumatoid Arthritis
- Sarcoma
- Chemo Induced Anemia and Chemo Induced Neutropenia (CIA/CIN)

The program experienced a 25.8% increase in the number of patients served totaling 7,310 during FY2008/2009. The CPR program has provided assistance to a total of 25,123 patients and provided more than \$50 million dollars in direct financial assistance since inception, April 1, 2004.

In FY2008/2009, the PAF CPR program implemented a secured, web-based application portal available on the CPR public website, designed to allow patients, family members and/or caregivers to enroll via the internet, minimizing enrollment time as well as offering real-time information on the availability of assistance in each disease category. The portal is available 24 hours a day and can be accessed on the CPR website at www.copays.org.

Patient Advocate Foundation would *like to thank the following donors for* their continued financial support of the Co-Pay Relief program in FY2008/2009:

























Schering-Plough

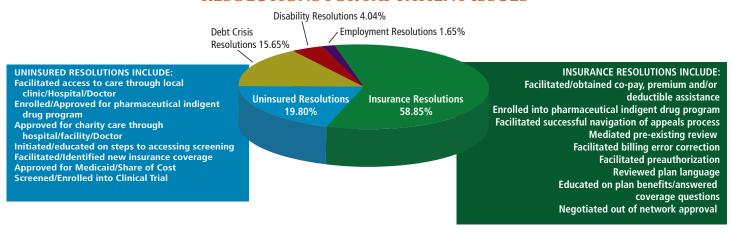


# DIRECT PATIENT SERVICES DIVISION

As well, on September 10, 2008, PAF received favorable modifications from the Office of Inspector General (OIG) to the PAF opinion to include expansion of the approved disease categories allowing the program to operate an additional 16 categories bringing the total approved disease states that PAF can offer co-payment assistance to 43. The OIG modification also provided expanded reporting capabilities to donors to include monthly disease fund utilization.

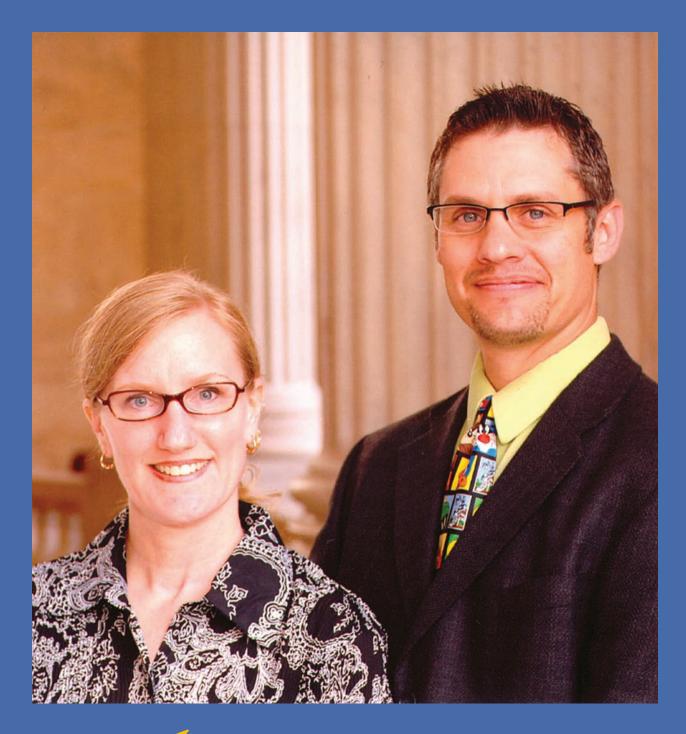
In February 2009, the CPR Program began offering Electronic Funds Transfer (EFT) as an additional payment method that can be utilized when the CPR program is making payments to providers, pharmacies and/or patients for the patient's required pharmaceutical co-payments.

## **RESOLUTIONS FOR PAF PATIENT ISSUES**



Meeting the needs of our patient population continues challenge our professional staff members to be more creative and persistent when identifying resolutions to the issues our patients face. The downturn of the economy has created a new population of uninsured patients who have lost coverage when their companies have closed while the available resources for patients confronting access to care issues continue to shrink. Despite the odds, our team of professional case managers and call counselors have been successful in finding resolutions to our patient's issues, often working with each patient and the key stakeholders in their circle of care over a sustained period of time until all of the access barriers have been overcome. In FY2008/2009 the number one category of resolutions achieved by our staff on behalf of the patients seeking our assistance were Insurance Resolutions (58.85%), a 13.45% increase over last fiscal year, including obtaining co-payment, deductible and premium assistance for patients, facilitating access to free drugs through manufacturer sponsored programs, providing benefit review and interpretation, facilitating appeals on behalf of patients, coordinating approvals for out of network transfers and second opinions, auditing and correcting medical coding and billing errors, and mediating the review of pre-existing condition based denials. The second largest category of resolutions were those brought to bear for our Uninsured population, classified simply as Uninsured Resolutions (19.80%), and include the facilitation of access, at times through the utilization of charity care, to prescribed healthcare through local clinics, providers and hospitals, accessing free drugs through manufacturer based programs, providing education and direction to facilities offering free or reduced price screenings, assisting with application to state Medicaid and/or SCHIPS programs, and, in some cases, identifying access to insurance coverage. Debt crisis resolutions (15.65%), Disability Resolutions (4.04%) and Employment Resolutions (1.65%) complete the top 5 broad categories of resolutions achieved on behalf of PAF patients in FY2008/2009.

As healthcare reform continues to be in the forefront of the news, the PAF staff, especially those who interact daily with patients, continue to ensure that those patients receive access to the care that they need. Regardless of the outcome of the reform package, PAF will remain a constant in patient advocacy, available and ready to help patients solve their insurance and healthcare access problems.



# Advocate

# 10th Annual Patient Congress

## June 24-25, 2009

Patient Advocate Foundation convened its 10<sup>th</sup> Annual Patient Congress on June 24-25, 2009 in Washington, DC. The two-day event attracted more than 173 patients, family member advocates, physicians, nurses and social workers – representing 46 states and the District of Columbia. This years Patient Congress drew heightened attention as the new administration turned its focus and efforts to national health care reform. While the attendees were in Washington for Patient Congress, both committee hearings and markups on proposed healthcare reform legislation were occurring which contributed to the ferver with which the attendees advocated for healthcare reform when they visited their members offices. Attendees learned how to use their voice to educate legislators on what the patient experience is in the current health care system and offered substantive suggestions for improvement.

Patient Congress attendees participated in a Capitol Hill briefing where they were provided with a bipartisan summary of the varying versions of proposed healthcare reform legislation being considered by the Congress, facilitated by a panel of staff members from Congressional offices and career policy experts. The attendees were also addressed by keynote speaker, the Honorable Debbie Wasserman Schultz (D-20<sup>th</sup>-FL), who spoke about her personal battle with breast cancer and the role that experience played in her efforts to introduce the Education and Awareness Requires Learning Early Act (EARLY Act) which would provide funding to implement a national education campaign about risks that young adult women (under 40) face from breast cancer, as well, it would provide assistance to young women who have the disease. She encouraged all of the attendees to make their voice heard by weighing in, with real life experiences, on the policital debate that is healthcare reform.



The Honorable Debbie Wasserman Schultz (D-20th-FL), US House of Representatives, discusses the EARLY Act she is sponsoring



Wendell Primus, Senior Policy Advisor to the Speaker of the US House of Representatives addresses attendees on current healthcare reform legislation



Attendees role play during the Hill Briefing session



Christopher Kush, CEO, Soapbox Consulting educating Patient Congress attendees on how to have an effective Hill Visit during the Capitol Hill Briefing



Eilene Frierson, NPAF State Policy Liaison from Pennsylvania, asking a question during the Hill Briefing

That evening, attendees had the opportunity to attend an Educational Expo and Reception. Representatives from the patient advocacy community and representatives from voluntary health care organizations and agencies were available to visit with attendees and to provide educational information.

## **Exhibitors included:**

- ASTRO
- Bladder Cancer Advocacy Network
- Breast Cancer Network of Strength
- Cancer Hope Network
- CaringBridge
- Centers for Medicare and Medicaid Services
- Colorectal CareLine
- Co-Pay Relief Program
- Día de la Mujer Latina, Inc.
- Geriatric Oncology Consortium/Grandparents Against Cancer
- International Medical Interpreters Association
- Kidney Cancer Association
- Lance Armstrong Foundation
- Leukemia and Lymphoma Society
- Men's Health Network



PAF staff is ready to welcome the attendees! (I to r) Vicki Storey, Fran Castellow, MSEd.-Patient Congress Chair, Jamilla Williams, Tami Lewis, RN, Gayle Petrick, Erin Moaratty, Jack Ennis

- National Center for Complementary and Alternative Medicine
- National Cervical Cancer Coalition
- Oncology Nursing Society
- Patient Advocate Foundation
- Sarah Lawrence College: Health Advocacy Program
- The Brain Tumor Awareness Organization
- The Mautner Project
- The Pancreatic Cancer Action Network
- The Wellness Community
- Women and Cancer Magazine
- Young Survival Coalition
- Coping Magazine
- Susan G. Komen For The Cure



Attendees learn about other non-profit advocacy groups during the Patient Congress Educational Expo



Susan G. Komen for the Cure presents their educational materials to attendees

# 10th Annual Patient Congress

On day two of the conference, Patient Congress participants, prepared by the Capitol Hill Briefing, where they were educated not only to the issue of healthcare reform, but also equipped with practical methods and strategies for conducting an effective Congressional visit, conducted personal visits with their Members of Congress from both the US House of Representatives and the US Senate. The Patient Congress attendees completed 200 meetings with Members of Congress and staff on Capitol Hill, including 97 Senate offices and 103 House offices, asking for their support for comprehensive National Health Care Reform in 2009. The principles that attendees addressed were:

- Universal Access to Health Care Coverage
- Ensure that Health Care Coverage is Affordable
- Improve the Quality of Health Care and Health Care Coverage
- Attain a Fair and Equitable Health Care System
- Make Health Care Portable

During the Dinner Symposium held Thursday evening, attendees heard from the Honorable Joe Courtney (D-2<sup>nd</sup>-CT), United States House of Representatives, the Honorable Allyson Schwartz (D-13<sup>th</sup>-PA), United States House of Representatives and Jon Sands, Vice President of Business Development, Roush Fenway Racing and a cancer survivor. A highlight of this year's Patient Congress Dinner Symposium was the opportunity for participants to hear from our Keynote speaker, Elizabeth Edwards, Senior Fellow, The Center for American Progress, Successful Author and Advocate for Children's Causes. Prior to the Dinner, Mrs. Edwards graciously autographed copies of the latest book, "Resilience: Reflections on the Burdens and Gifts of Facing Life's Adversities" for all of our attendees. Her story of courage, perserverence, and humality left an undeniable impression of hope on all in attendance.



Nancy Davenport-Ennis with speaker Congressman Joe Courtney (D-2nd-CT) following his presentation



Keynote Speaker Elizabeth Edwards describes the journey of her battle with cancer



Elizabeth Edwards with two Patient Congress attendees



Jon Sands with Roush Fenway Racing tells Patient Congress attendees how he overcame his diagnosis of cancer



The Honorable Allyson Schwartz (D-13th-PA) addresses Patient Congress attendees during the Dinner Symposium

Attendees left Patient Congress invigorated and ready to take the message back to their home states. In their own words, attendees had to say:

"Patient Congress was an eye opener, not only regarding patient advocate issues, but also about the legislative process. This year is especially exciting because Healthcare Reform is eminent and because of the new administration and president. This is the era of hope."

"I liked that the Members of Congress listened to our stories and really were interested in what we had to say."

"Patient Congress was a great learning experience, I learned that my opinion and vote DOES COUNT!"

A special thanks to the Members of the United States Congress who served as Honorary Chairs for the 10<sup>th</sup> Annual Patient Congress

## UNITED STATES SENATE

Senator Max Baucus (D-MT)

Senator Thad Cochran (R-MS)

Senator Charles Grassley (R-IA)

Senator Arlen Specter (D-PA)

Senator Tim Johnson (D-SD)

Senator Michael Enzi (R-WY)

Senator Mike Crapo (R-ID)

Senator Maria Cantwell (D-WA)

Senator Saxby Chambliss (R-GA)

Senator Benjamin Cardin (D-MD)

Senator Robert P. Casey (D-PA)

Senator Sheldon Whitehouse (D-RI)

Senator Roland Burris (D-IL)

Senator Edward Kennedy (D-MA)

Senator Lisa Murkowski (R-AK)

Senator Dianne Feinstein (D-CA)

Senator Daniel Inouye (D-HI)

Senator Jim Webb (D-VA)

Senator Kay Bailey Hutchison (R-TX)

Senator Mark R. Warner (D-VA)

Senator Mark Begich (D-AK)

Senator Bernard Sanders (I-VT)

Senator Joseph I. Lieberman (I-CT)

Senator Mitch McConnell (R-KY)

Senator Byron Dorgan, (D-ND)



Kim Williams, NPAF staff member, Herb Perry from Nevada and Donna Adkins, PAF staff member enjoying the Patient Congress dinner reception



Lori Williams, PhD, PAF Scientific Board Member, Leah Arnett, RN, PAF Executive Board Secretary, Elizabeth Edwards and Rob Rifkin, MD, Scientific Board Chair during the Dinner Symposium Reception



Congressman Ron Paul (R-14th-TX) and members of the Patient Congress Texas delegation

# PATIENT CONGRESS HONORARY CHAIRS

## United States House of Representatives

Representative Nick J. Rahall, II (D-3<sup>rd</sup>-WV)

Representative John Lewis (D-5th-GA)

Representative Fred Upton (R-6th-MI)

Representative Donald M. Payne (D-10th-NJ)

Representative Rosa DeLauro (D-3rd-CT)

Representative Ed Pastor (D-4<sup>th</sup>-AZ)

Representative Anna G. Eshoo (D-14th-CA)

Representative Bob Goodlatte (R-6th-VA)

Representative Gene Green (D-29th-TX)

Representative Peter Hoekstra (R-2<sup>nd</sup>-MI)

Representative Carolyn Maloney (D-14th-NY)

Representative Lucille Roybal-Allard (D-34th-CA)

Representative Lloyd Doggett (D-25th-TX)

Representative Zoe Lofgren (D-16th-CA)

Representative Diana DeGette (D-1st-CO)

Representative Ron J. Kind (D-3rd-WI)

Representative Loretta Sanchez (D-47th-CA)

Representative Shelley Berkley (D-1st-NV)

Representative Barbara Lee (D-9th-CA)

Representative Michael Honda (D-15th-CA)

Representative Candice Miller (R-10th-MI)

Representative Chris Van Hollen (D-8th-MD)

Representative Geoff Davis (R-4<sup>th</sup>-KY)

Representative Bruce Braley (D-1st-IA)

Representative Gerry Connolly (D-11th-VA)

Representative Eleanor Holmes Norton (D-DC)

Representative Ed Pastor (D-4th -AZ)

Representative Jim Himes (D-4th-CT)

Representative John Dingell (D-15th- MI)

Representative Raul M. Grijalva (D-7th-AZ)

Representative Doris Matsui (D-5th-CA)

Representative Eric I. Cantor (R-7<sup>th</sup>-VA)

Representative Cathy McMorris Rodgers (R-5th-WA)

Representative Robert J. Wittman (R-1st-VA)

Representative Bobby Scott (D-3<sup>rd</sup>-VA)

Representative James P. Moran (D-8th-VA)

Representative Henry A. Waxman (D-30th-CA)

Representative Ginny Brown-Waite (R-5th-FL)

Representative Sander Levin (D-12th-MI)

Representative Howard Coble (R-6th-NC)

Representative Allyson Y. Schwartz (D-13th-PA)

Representative Charlie Wilson (D-6th-OH)

Representative Steven LaTourette (R-14th-OH)



Senator Robert Bennett (R-UT) with Kermit Heid, Rob Rifkin, MD and Nancy Davenport-Ennis



Patient Congress attendees meet with the Health Liaison in Congressman John Kline's (R-2nd-MN) office



Senator Sam Brownback (R-KS) with members of the Patient Congress Kansas delegation

Representative Joe Sestak (D-7<sup>th</sup>-PA)

Representative Christopher Lee (R-26<sup>th</sup>-NY)

Representative Eddie Bernice Johnson (D-30<sup>th</sup>-TX)

Representative Kendrick B. Meek (D-17<sup>th</sup>-FL)

Representative Gregory Meeks (D-6<sup>th</sup>-NY)

Representative Tim Murphy (R-18th-PA)

Representative Jo Ann Emerson (R-8<sup>th</sup>-MO)

Representative Tom Latham (R-4<sup>th</sup>-IA)

Representative Phil Gingrey, MD (R-11<sup>th</sup>-GA)

Representative Steven Rothman (D-9<sup>th</sup>-NJ)

Representative Deborah Halvorson (D-11<sup>th</sup>-IL)

Representative John Linder (R-7<sup>th</sup>-GA)

Representative Sue Myrick (R-9<sup>th</sup>-NC)

Representative Judy Biggert (R-13<sup>th</sup>-IL)

Representative Thomas E. Petri (R-6<sup>th</sup>-WI)

Representative Robert A. Brady (D-1st-PA)

Representative Adam H. Putnam (R-12<sup>th</sup>-FL)

Representative Chaka Fattah (D-2<sup>nd</sup>-PA)

Representative Charles Gonzalez (D-20th-TX)

Representative Dan Boren (D-2<sup>nd</sup>-OK)

Representative Louise McIntosh Slaughter (D-28th-NY)

Representative Dave Reichert (R-8<sup>th</sup>-WA)

Representative Russ Carnahan (D-2<sup>nd</sup>-MO)

Representative Gwen Moore (D-4th-WI)

Representative Kay Granger (R-12<sup>th</sup>-TX)

Representative Marcia L. Fudge (D-11<sup>th</sup>-OH)

Representative Sheila Jackson Lee (D-18<sup>th</sup>-TX)

Congressman Chaka Fattah, (D-2<sup>nd</sup>-PA)

Congressman Dennis Kucinich, (D-10<sup>th</sup>-OH)

# A Special Thanks goes to the Ardent Supporters of the 10th Annual Patient Congress:

- AmerisourceBergen
- Amgen Oncology
- Boehringer Ingelheim
- Eli Lilly and Company
- Genentech
- GlaxoSmithKline
- Lance Armstrong Foundation
- Novartis
- Pfizer Oncology
- sanofi-aventis
- Schering-Plough
- US Oncology



Nancy Davenport-Ennis, CEO, Patient Advocate Foundation and National Patient Advocate Foundation closing the 10th Annual Patient Congress.



# SCHOLARSHIPS FOR SURVIVORS ACADEMIC AWARD PROGRAM

The Scholarships for Survivors will provide \$33,000 in scholarship funds for 2009 - 2010. This year's Scholarships for Survivors recipients are:

# THE CHERYL GRIMMEL AWARD

Insup Lee

School: Harvard College

## THE MONICA BAILES AWARD

Sadie Byboth

School: Louisiana State University

# THE JIM MEADE & LUKE BARLOWE AWARD

Nicholas Harper

School: Bellarmine University

# THE KAREN L. REEDER AWARD

Kristopher Adame

School: New River Community & Technical College

## THE ROBIN PRACHEL AWARD

Dylan Feierabend

School: College of the Redwoods

## THE JO ANN DAVIS AWARD

Abby Schafer

School: Marywood University

# SCHOLARSHIPS FOR SURVIVOR RECIPIENTS

Tenisha Avila

School: Fresno Pacific University

Gregory Johnson

School: Colorado School of Mines

**Hunter Durfee** 

School: Keene State College

Kahina Louis

School: University of Florida

Mary Stiddom

School: Jackson State Community

College



Nancy Davenport-Ennis, CEO, first time scholarship recipient Kahina Louis who is attending the University of Florida, Rob Rifkin, MD, PAF Scientific Board Chair and Ruth Anne Reed, Scholarship for Survivors Chair celebrate Kahina's acceptance of a Scholarship for Survivors

At this year's 10<sup>th</sup> Anniversary celebration at Patient Congress, Patient Advocate Foundation hosted the Scholarships for Survivors Academic Award Program presentation on the final night of activities. The purpose of the program is to provide financial support to patients who are 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.

This year, Patient Advocate Foundation recognized Kenny Thomas who completed his course of study and graduated from University of Louisville.

"PAF played a vital role in my college career this year by giving me the necessary financial means and support to make it through college. I have traveled a tough road which made me a better person. I look back and remember all the great people along the way this year that helped me and encouraged me to keep trying even when I wanted to give up sometimes or got lazy. I have been given another chance at living life and I am doing all I can to make sure it's healthy and successful. I have truly been blessed and I am trying to open doors and do nice things as others have done for me. Again I want to thank PAF for all the support and love that they have shown me and my family. Patient Advocate Foundation is a great organization and I am proud that you choose me for the Jim Meade and Luke Barlowe Scholarship."



Sade Byboth, shares with the audience her experiences from her freshman year in college at Louisiana State University



Bellarmine University student Nick Harper talks about how the Scholarship for Survivors program has made it possible for him to pursue his higher education goals



Hope

# 8TH ANNUAL A PROMISE OF HOPE AFFAIR



Patient Advocate Foundation Executive Round Table members in their finest denim and diamonds.

Dynelle Lunsford, Fran Castellow, Carey Waldrip, Sally Blanchard, Beth Darnley, Bill Nason, Alan Richardson, Jack Ennis, Nancy Davenport-Ennis, Erin Moaratty



Submitting that Winning Bid!



Bidding during the Scholarships for Survivors portion of the live auction.



On February 28, 2009, Patient Advocate Foundation held its 8<sup>th</sup>Annual *A Promise of Hope Affair* with a theme this year of Denim and Diamonds where our guests were able to wear their finest denim and/or formal attire. We were joined by 370 attendees, including the PAF Executive, Scientific and Honorary Boards of Directors, local businesses, PAF staff members and Partners in Progress representatives.

Attendees were able to bid on over 300 auction items with a fair market value of over \$50,000.00. Paul Haymes served as our auctioneer that evening during the live auction, helping to raise over \$14,000.00 for PAF's Scholarships for Survivors program.



Beth Darnley, President-Mission Delivery, speaks to the crowd about the services that PAF offers to patients.



Fran Castellow, President-Operations, welcomes the attendees to A Promise of Hope Affair



Nancy Davenport-Ennis, CEO, Pamela Bennett and Kim Tiller with Purdue Pharma and Fran Castellow, President-Operations enjoy the VIP Reception.



Living Statues, "Statuarium" pose for our guests as they enter the ballroom for dinner.



Is it a statue? Or is it a real person?



Our three statues in "Statuatium" close the show with the theme song "Oklahoma".

Our guests were entertained as they walked into the ballroom by three "living" statues, Staturarium, who burst in to country and western song, startling many of the guests who thought they were true statues. After dining on London Broil and BBQ Shrimp Skewers, our guests were able to dance the night away to the sounds of "Slapwater", a popular local band.

Barbara Butler, a local patient that PAF had recently assisted, spoke to the crowd, telling her story of her cancer diagnosis and how PAF had helped her through her treatment and insurance issues. Congressman Robert C. "Bobby" Scott (D-3<sup>rd</sup>-VA) and Congressman Rob Wittman (R-1<sup>st</sup>-VA<sup>t</sup> both addressed the crowd and Donna Adkins, Chair of our Auction Committee presented Nancy Davenport-Ennis, CEO and Jack Ennis, Chief Development Officer and Co-Founders of PAF with a Proclamation from the Commonwealth of Virginia proclaiming April 4<sup>th</sup> to be Patient Advocate Foundation Day, the date that PAF was founded in 1996.



Becca Fifelski and Lindsey Arndt entertain our guests at the VIP Reception

Through the support of local businesses, Board of Directors and Partners in Progress, this year's *A Promise of Hope Affair* was able to raise \$327,724.00 through donations, sponsorships, auction bids and in-kind donations for PAF's provision of direct services to help patients obtain access to quality health care.



Slapwater entertaining the attendees



Congressman Robert Scott (D-3<sup>rd</sup>-VA) is joined by Alan Richardson, *A Promise of Hope Affair* Chair after Congressman Scott addressed our attendees.



Nancy Davenport-Ennis, Congressman Rob Wittman (R-1st-VA), Beth Darnley and Jack Ennis



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# 8TH ANNUAL A PROMISE OF HOPE AFFAIR

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The Silent Auction is in full swing.

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Alan Richardson, Chair of *A Promise of Hope Affair*, recognizes Event Sponsor Amgen Oncology and representative Kathryn West.



Sally Blanchard (r) presents Marcie Mutti GlaxoSmithKline's Event Sponsor plaque.



Jack Ennis presents an Event Support plaque to Kesslyn Smith with sanofi-aventis.



Pamela Bennett with Purdue Pharma is presented her Event Sponsor plaque by Pam Cleck.



Bruce Edelen-Eli Lilly, Beth Darnley-PAF, Linda House-Eli Lilly and Susan Fox-Eli Lilly, Event Sponsors

# 8TH ANNUAL A PROMISE OF HOPE AFFAIR

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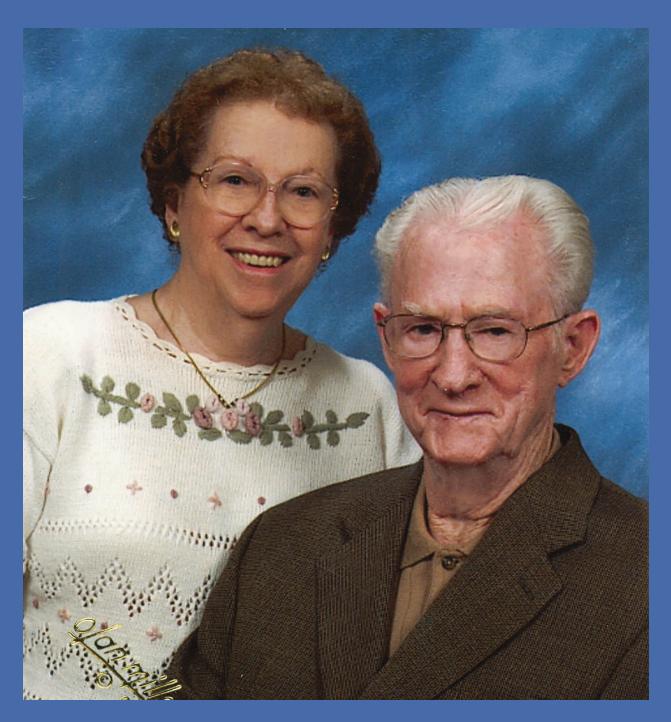
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Nancy Witt

#### COMBINED FEDERAL CAMPAIGN

PAF is a participant 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 though the use of payroll deduction. PAF's CFC number is 10681. You are also able to designate Patient Advocate Foundation with your United Way campaign. Ask your United Way representative on the correct procedure to designate PAF as it may vary from United Way to United Way.



**Lisa P**Breast Cancer
Cartersville, GA

Randy Yocum

"I'm a single mother with Terminal Breast Cancer. My helper at Patient Advocate Foundation was Margie Griffin; she was so nice and helpful with every question and even provided information on program in my area I had no idea existed. She helped me get Medicaid through in time for my first Chemo

Treatment, which was one day and starting SSI Disability. She stayed on the phone with me through interviews and explained everything. She calls back promptly when I call her with a question and she was supportive in every way possible. If not for Patient Advocate Foundation, I would still be searching for the proper help I need, instead I am receiving it. Thanks to Patient Advocate."

## PAF FINANCIAL STATEMENTS

#### Patient Advocate Foundation

#### Statements of Financial Position

June 30,	2009	2008
Assets		
Current assets		*\
General operating cash and cash equivalents	\$ 2,903,744	\$ 3,338,443
Restricted CPR cash and cash equivalents	20,579,341	18,806,169
Unconditional promises to give	45,325	5,223
Interest receivable	73,050	75,639
Service contract receivable	116,074	(a <del>-</del>
Inventories	76,237	46,42
Prepaid expenses	75,867	88,10
Investments	1,876,093	1,829,580
Total current assets	25,745,731	24,189,584
Property and equipment - net	895,208	796,651
Other assets		
Refundable deposits	15,463	11,40
	\$26,656,402	\$24,997,63
Liabilities and Net Asset	s	
Current liabilities		
Current portion of obligation under capital lease	\$ 58,660	\$ 54,293
Accounts payable and accrued expenses	360,238	293,263
Deferred revenue	1,957,297	2,225,270
Accrued vacation leave	313,508	264,712
Total current liabilities	2,689,703	2,837,538
Long term liabilities		
Obligation under capital lease-less current portion	186,805	245,464
Total liabilities	2,876,508	3,083,002
Unrestricted	1,225,417	1,170,983
Temporarily restricted	20,579,341	18,806,169
Permanently restricted	1,975,136	1,937,483
Total net assets	23,779,894	21,914,635
	\$26,656,402	\$24,997,637

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

Patient Advocate Foundation

## Statements of Activities

Years Ended June 30,		20	2009			30	2008	
	Unrestricted	Temporarily Restricted	Permanently Restricted	Total	Unrestricted	Temporarily Restricted	Permanently Restricted	Total
Revenues, gains and other support Contributions								
Grants	\$ 4,592,337	\$ 12,106,822	S	\$ 16,699,159	\$3,478,484	\$ 10,917,427	S	\$ 14,395,911
Private and public donations	129,933			129,933	148,178	•	1	148,178
Donated services and materials	136,234	,	J G	136,234	146,480	3	•	146,480
Co-Pay Relief administration	2,880,956	ì	3.	2,880,956	3,122,222	э	3	3,122,222
Patient Congress	204,715	•		204,715	211,634	J	Ø	211,634
Promise of Hope	267,297			267,297	278,079	3)	212	278,079
Service contract	331,927	1	3.	331,927	1	(C)	ı	e Č
Special events	132,974	•	ė	132,974	90,553	U	F:	90,553
Investment income	490,847	•	37,653	528,500	797,721	ı	56,921	854,642
Net assets released from restrictions	10,333,650	(10,333,650)	r.	·	10,542,590	(10,542,590)	í	ì
Total revenues, gains								
and other support	19,500,870	1,773,172	37,653	21,311,695	18,815,941	374,837	56,921	19,247,699
Expenses								
Program services								
Patient services	5,053,936	•	i	5,053,936	4,396,300	£	II.	4,396,300
Co-Pay Relief	12,506,046	e	ï	12,506,046	13,130,405	Ē		13,130,405
Service contracts	332,963	·		332,963	ī	ï	1	
Patient Congress	•	•	i	,	329,945	Ĩ	9	329,945
Scholarships	٠	i	i	a	90,741	ï	э	90,741
Supporting services:								-
Management and general	862,809	31	•	862,809	1,050,935	•	Э.	1,050,935
Fundraising	690,682	*	1	690,682	239,772	i		239,772
Total expenses	19,446,436		ï	19,446,436	19,238,098	i	×	19,238,098
Change in net assets	54,434	1,773,172	37,653	1,865,259	(422,157)	374,837	56,921	109'6
Net assets - beginning of year	1,170,983	18,806,169	1,937,483	21,914,635	1,593,140	18,431,332	1,880,562	21,905,034
Net assets - end of year	\$ 1,225,417	\$ 20,579,341	\$ 1,975,136	\$ 23,779,894	\$1.170,983	\$ 18,806,169	\$ 1,937,483	\$ 21,914,635
				A CONTRACTOR NAMED AND ADDRESS OF THE PERSON				

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

### PAF STAFF FY2008/2009

#### **Executive Leadership:**

Nancy Davenport-Ennis, Chief Executive Officer Fran Castellow, MSEd., President, Operations Beth Darnley, President, Mission Delivery William Nason, Chief of Contracting, Business Forecasting, and Facilities Officer

#### **Administrative Support Staff:**

Chanda Cox Judi Roberson Mary Tilles

#### **Communications:**

Tracy Andrus, Supervisor, Communications Department Megan Bradshaw Tricia Smithers

#### **Corporate Development:**

John H. Ennis, Jr., Chief Development Officer Alan Richardson, Chief Development Operations Officer

#### Finance:

Dynelle Lunsford, Chief Financial Officer Debbie Andrus Stacia Foreman Metise Council Vicki Huxford

#### **Human Resources:**

Sally Blanchard, Chief Human Resource Officer Ruth Anne Reed

#### **Information Technology:**

Carey Waldrip, Chief Information Technology Officer Edwin Anderson Chad Berg Kevin Cox Bryce Lohr

Victoria Doheny Gregory Foster Elena Ganeko Jason Green Alan Kapadia Russ Stewart

#### **Mission Delivery Executive Staff:**

Erin Moaratty, Chief Special Project Officer Kendra Bluhm, Chief Project Management Officer

#### **Direct Patient Services:**

Pat Jolley, RN, Patient Services Supervisor Donna Adkins Shauna Hatfield Carolyn Andrews, LPN Jacqueline Beard Brendan Bietry Deirdre Cappe Liz Cary Yashia Clarke Shelby Cornick Cynthia Espenshade Stella Estrada, LVN Wanda Febus Iane Garfield Lakendra Green Laurel Gregory Margie Griffin Cheryl Grizzle Donna Haraburda Michelle Herbert Courtney Jones Patricia Jones Vonya Journiette Lisa Kelley Tami Lewis, RN Leigh Loyd Sandra McAllister Danna Mobley Tammy Neice, RN Patrice Osborne, RN Gayle Petrick Avis Potter Nansi Rivas Nicole Robinson Claudia Sandoval Michelle Shanks ShaCole Simmons **Judith Storey** Tanya Walker, RN

Jamilla Williams Renee Zeigler, RN

#### Co-Pay Relief Program:

Pam Cleck, Director

Beverly McNearly-DaRavalliere, Assistant Director

Lisa Wright

Mary Altomare Milagros Blanco Stephanie Bland LaToya Blizzard **Jackie Bruckheimer** Carly Coleman Cynthia Edwards Laura Evans Samantha Fries **Joyce Grimes** Viola Jackson Angela Johnson Tracie Karafa Willie Lovett Michelle McMillian Christina McKinney Rita Robinson Marcie Murillo Rocquel Robinson Tina Santiago Sandra Scott Karen Seitz Lewis Shivers Melissa Taylor Sherri Walker Tricia Turner

Candis Windsor

Tara Girard, Director

Johnnie Burke, III Trisha Cochran
Mary Ellen Fleeger Joan Gore
Sarah Lane Deborah Monelly Erica Rosenthal
Danielle Rountree Linda Shird
Whitney Thornton Michael Trapp

#### Med CareLine Program:

Elaine Abrams, RN

Amber Davies Carlette Hattett
Kenneth Jacobs Elaine Martinez
Cheryl Nowell



# New Beginnings

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## SAVE THE DATE

## 9TH ANNUAL A PROMISE OF HOPE AFFAIR

February 27, 2010 Newport News Marriott at City Center Newport News, Virginia

"Mid-Winter Beach Party" www.promiseofhope.net

## 11TH ANNUAL PATIENT CONGRESS

June, 2010 Washington, DC www.pc.patientadvocate.org

## 2010-2011 Scholarship for Survivors

Application Deadline: April 12, 2010 www.patientadvocate.org

Listed Under "Programs" Section





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#### **MISSION STATEMENT**

Patient Advocate Foundation is a national non-profit 501(c) organization that serves as an active liaison between the patients and their insurer, employer and/or creditors to resolve insurance, job retention and/or debt crisis matters relative to their diagnosis through case managers, doctors and healthcare attorneys. Patient Advocate Foundation seeks to safeguard patients through effective mediation assuring access to care, maintenance of employment and preservation of their financial stability.