# ANNUAL REPORT 2011-2012



Solving Insurance and Healthcare Access Problems | since 1996



# **MISSION STATEMENT**

Patient Advocate Foundation was established in 1996 as a national 501(c)3 organization with a mission of "safeguarding patients through effective mediation assuring access to care, maintenance of employment and preservation of their financial stability." PAF serves as an active liaison between 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 health care attorneys.

Patient Advocate Foundation has been helping patients solve their insurance and health access problems through our Direct Patient Services Division for over 16 years. During its first year of operations, PAF assisted 157 patients in a 10x10 foot warehouse space. In FY 2011/2012, PAF assisted 127,808 patients in an over 37,000 square foot national headquarters located in Hampton, Virginia and by staff located in lowa, Florida, California and Texas. Services are provided by our professional case management staff, the Co-Pay Relief (CPR) staff and the MedCareLine staff. Case management was and continues to be PAF's main core competency with Co-Pay Relief emerging as a second core competency in 2004.





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# HOW DO YOU MEASURE A YEAR?

Five hundred twenty-five thousand six hundred minutes, Five hundred twenty-five thousand moments so dear. Five hundred twenty-five thousand six hundred minutes, How do you measure, measure a year?

In daylights, in sunsets, in midnights In cups of coffee In inches, in miles, in laughter, in strife.

In five hundred twenty-five thousand Six hundred minutes How do you measure A year in the life?

How about love? How about love? How about love? Measure in love Seasons of love. Seasons of love.

Five hundred twenty-five thousand Six hundred minutes! Five hundred twenty-five thousand Journeys to plan. Five hundred twenty-five thousand Six hundred minutes How do measure the life Of a woman or a man?

In truths that she learned, Or in times that he cried. In bridges he burned, Or the way that she died.

It's time now to sing out Tho' the story never ends Let's celebrate Remember a year in the life of friends Remember the love! Remember the love! Seasons of love!

Music and Lyrics "Seasons of Love" from Rent by Jonathan D. Larson



# **GREETINGS FROM OUR CHIEF EXECUTIVE OFFICER AND CHAIRMAN OF THE BOARD** Nancy Davenport-Ennis

It has been said that the measure of a man is not what he takes from this world, but rather it is what he leaves for this world or as Robert South (1634-1716) expressed "If there be any truer measure of a man than by what he does, it must be by what he gives." The professional staff at Patient Advocate Foundation gave their professional services to 127,808 patients in this fiscal year period of July 1, 2011 through June 30, 2012 representing a 44.85% increase in demand since last

fiscal year. These cases required more than 1.4 million case contacts to achieve resolution to their issues, representing an increase of 29.10% increase over last fiscal year. Our professionals are finding these solutions in an increasingly complex world, made more so recently, by the compression of charity care at all levels, including loss of non-profit programs that had supported many of the at-risk populations, reduced benefits in plans both in the commercial and government sector and the continued increase in costs of healthcare services that drive higher out-of-pocket expenses for the patients we serve.

Routinely, we are reminded at Patient Advocate Foundation of Martin Luther King's perspective when he said "The ultimate measure of a man is not where he stands in moments of comfort and convenience, but where he stands in times of controversy." The PAF professional team stands firm in this time of shrinking financial resources and increased demand in solving access issues for patients and commends our Congress and Administration for addressing insurance reforms that are improving lives for the patients we serve. The addition of coverage for children with pre-existing conditions reduced our pediatric population this year over last year and the addition of children up to the age of 26 on parent's policy, produced more insured patients in this demographic than in years past. The addition of Pre-existing Condition insurance Plans for those with pre-existing conditions added a safety net for those who had lost jobs, were not eligible for COBRA benefits and due to their diagnosis of a chronic health condition had to maintain health insurance to access treatment assisted many of those whom we served with gap services.

The complexity of referrals to PAF illustrates the united effort of multiple healthcare stakeholders and individuals to find solutions as referral sources this year included national insurance companies, an increase in the federal government referrals both agencies and elected officials, state Medicaid programs, a large increase in non-profit patient organization referrals and steady growth in physician referrals culminating with almost ten percent of our referrals from national media. This year, our patient services have seen controversy in the issues our patients are bringing to us as we note that 80% of our patients have household income in this reporting period of less than \$36,000.00 annually while 66% of our patients were facing insurance issues. This affirms that the patients we serve are playing by the rules as they are working, they do have insurance and yet, when they become ill, the benefits are not meeting the need. The good news is that we are finding solutions so that these patients can adhere to treatment protocols and in so doing, joining our colleagues in the national healthcare stakeholder groups to unite in improving access, reimbursement and coverage.

This 2011/2012 Annual Report illustrates that the donor community has worked very deliberately to meet the needs of patients with co-pay relief issues and to support direct case management services for which we acknowledge and thank each of you. Our Annual Report also illustrates a year that ended with increased revenue over budget forecast with increased demand for direct patient service support that drove our expenses over budget for this fiscal year. Fiscal management of PAF has resulted in annual audits reports that cite an *Continued Page 4* 



# A MESSAGE FROM OUR BOARD PRESIDENT Dennis A. Gastineau, MD

In a time when many non-profit organizations have experienced great difficulties sustaining their missions, I am pleased that Patient Advocate Foundation has been able to continue the mission of serving people with cancer and chronic disease. The organization has been able to carefully conserve resources and make adjustments to changes in programs in a very timely fashion, continuing to increase the efficiency of delivering the needed services to those it serves.

We have seen dramatic changes already in the health care insurance industry, many anticipating changes expected in the healthcare laws. While there have been many benefits, including elimination of pre-existing conditions and lifetime limits, the durability of these changes remains uncertain.

As providers continue to consolidate, the greater challenge for rural organizations and access for those living in rural areas only increases. We continue to pursue and encourage models of care that will allow access to immediate and also specialty care to those who may have limited mobility or ability to travel to medical centers.

Patient Advocate Foundation has continued to expand partnerships with other organizations that share our objectives while maintaining our strong culture of attention and care to those in need of services.

After more than sixteen years and in very challenging times Patient Advocate Foundation continues on a path of fiscal efficiency and responsibility to prepare for service to those in need, who, no matter the public policy, will continue to have need.

### Dr. Dennis Gastineau

Administrative Overhead expense of 5.4%. This constrained management of resources has positioned PAF favorably for 2012/2013. Charity Navigator recognized PAF in May of 2012 with our third consecutive 4 Star Rating, the highest awarded by this national evaluation program with only 9% of charities achieving this level of recognition.

Recently, I received a letter from Martha Petit, who serves as a Coordinator of Family Services and Palliative Care at the Peninsula Cancer Institute and Riverside Cancer Infusion Center in Virginia. She observed "The staff from The Patient Advocate Foundation has stepped up to provide excellent information and support to all involved, including those of us who assist the patients and families with their journey in the world of cancer. It has been said, information is power. To give power to and to support those who are seeking answers, whether they seek out of need or of fear, is a noble cause. And it is for these many acts of empowerment, I wish to express my gratitude." She has it right. It is to the staff of PAF, our Board of Directors, our donors who are our friends to whom we owe recognition in this annual report for all that is reported herein and for the past, present and future they have defined for the patients we serve.

With gratitude,

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Nancy Davenport-Ennis CEO

# **BOARD OF DIRECTORS**

### **EXECUTIVE BOARD**

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Patient Advocate Foundation

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Director Program Coordinator & Associate Professor School of Nursing Clemson University

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President, Clinical Services and Chief Medical Officer HCA, Inc. (Hospital Corporation of America)

# Katrina Jacobs for patient, Deborah Jacobs, Duodenal Cancer

Raleigh, NC

Words cannot describe how grateful I am for PAF and case manager Gayle Petrick. I came to know about PAF through The American Cancer Society when my mother could not access the care that she needed. I was very hesitant to call because of the obstacles that we had faced in my mother's care since her diagnosis in the summer of 2011. We were desperate as a family to do what we could to extend my mother's days on Earth, especially since she had lost her own mother to the same disease on June 24, 2011. We weren't ready to give up that easily. From the time I placed the call, the receptionist couldn't have been any nicer when she answered the phone. This put me at ease and I was able to give the information that was needed to start a file on my mother. When I was told to expect a call within 72 hours, it happened. We didn't have to wait weeks on end to hear from a live person, I felt like we finally had someone in our corner that was going to help us out. Ms. Gayle Petrick was extremely kind and patient with my sister and me as we gave her the necessary information. Ms. Petrick kept the line of communication open with us via phone and e-mail. We were kept abreast of what she was dong. I will never forget receiving a voicemail from Gayle in which she said, "I just wanted to let you know that I haven't forgotten about Deborah and I am still working on her case." Again I felt like we had an ally in this fight which was the contrary to what we faced working with certain medical professionals and the healthcare system in general.

My mother's oncologist had worked out a way in which she could receive chemotherapy again. After letting Gayle know, I received a call back stating that it would be time to close my mother's case as access to care had been restored which was our goal from the beginning. Gayle informed me that if we should ever have any other issues that we could once again contact PAF for assistance. I thank God for this organization as I know that my mother is only one of millions of Americans facing issues with the healthcare system. To all whom are involved my family and I wish to say thank you and God bless you all for working on our behalf.



Rev. Berlin Jenkins, Stage 4 Colon Cancer Little Elm, TX

We were new to this health challenge. It was devastating and very frightening. I was so lost! You helped me start accepting and move towards fighting to "live". You provided much help, comfort, organization and a sense of support. You helped me to know HELP is available!



# A LETTER FROM THE PRESIDENT, MISSION DELIVERY

Beth Patterson

In 2000 I joined the Patient Advocate Foundation (PAF), intent on working every day to help individual patients who were weakened by illness, burdened by practical worries and concerned about accessing the care necessary to restore their health, my job at that point was a case manager. My first year was measured in small increments, one case resolution, one thank you, one patient, one family at a time until finally those efforts were quantified numerically for an annual report and I realized that our small team had achieved a substantial patient service number. Today I manage the case management division where I started, along with our Co-Pay Relief Program, Contract Vendor Services Division and the multiple partnerships and initiatives that fall under the broad Mission Delivery umbrella, and although my position has changed my personal measurement of success has never changed over the years, my reflection always returns to the individuals who have been touched in a positive way as a result of having a dedicated professional work on their behalf at a time when they are vulnerable and unable to do it alone.

As I look back at the progress of our Mission Delivery Division during FY2011/2012 three themes prominently emerge, meaningful service expansion that was built on PAF's established core competencies, increased efficiencies within all divisions ensuring that we are conservative stewards of the generous donations provided by our partners and an unwavering focus on meeting the myriad of both traditional and emerging needs being brought to us by our diverse patient population. Through changes to our operational model and the implementation of cutting edge technology solutions our Co-Pay Relief Program saw a 168.43% increase in the number of patients approved for financial assistance over the past year. Our Case Management Division experienced further diversification in service offerings, launching our first partnership with a national health insurer, the *Clinical Appeals CareLine*; a national outreach program, funded by the Susan G. Komen for a Cure Foundation, to provide education to Hispanic/Latino breast cancer patients; the *Narcolepsy CareLine Program*, a geographically targeted program, funded by the American Cancer Society, providing case management support to disparate breast cancer patients; and the *PAF/LIVESTRONG Navigation Center Partnership* in Austin, Texas. According to the numbers, PAF's total patient case count increased by 44.85% this year over last but the real story lies in the number of individual lives that were touched, they number more than 127,000.

The past year has been one of transition for our entire nation as phased healthcare reforms were implemented under the Affordable Care Act, attention became focused on a Presidential election, certain segments of the economy showed glimmers of improvement while other segments showed continued decline and PAF professionals entered a continuous pattern of learning as healthcare reimbursement and delivery patterns shifted yet again, insurance coverage options changed and patients had more participation with and accountability for their healthcare decisions than ever before. Our case managers assisted young adult patients, up to age 26, with enrollment on their parent's insurance plans, helped facilitate or directly obtained alternate insurance coverage for thousands of patients and secured more than \$26,000,000.00 in debt relief, a 12.04% increase over last year, for patients and providers nationwide.

PAF is uniquely positioned to begin providing support over the coming year to those patients who will be entering the insurance marketplace and seeking education about the newly formed insurance exchanges. As a trusted source for providers, non-profit organizations, government agencies and patients for the past 16 years we stand ready, with your support, to meet the future needs of patients, never wavering from our commitment to ease the many burdens brought by illness one individual at a time. How does one measure a year, I suggest that you merely count the sphere of influence of just one patient and know that the impact of a single good deed performed for another ripples far beyond the immediate beneficiary, thus creating a more compassionate environment for us all.

I sincerely thank all of you who have financially supported the work of Patient Advocate Foundation and look forward to continuing our collaborations over the coming year. I would also like to acknowledge the outstanding efforts of some key members of the Mission Delivery team including Erin Moaratty, Chief of Mission Delivery, Pam Cleck, Chief of Financial Assistance Programs, Donna Haraburda, Case Management Director, Beverly McNearly-DeRavalliere, Co-Pay Relief Director and Courtney Jones, Contract Vendor Director, for without their leadership PAF could not deliver the vast amount of quality services to patients that we deliver each year.

Warm Regards~

Beth Patterson, President, Mission Delivery

# Susan Denard for Curtis Denard, patient, Stage 4 Colon Cancer Jacksonville, FL

I want to take a few moments to express our sincerest appreciation for the generosity of this organization. I do not know from where the funds come, but whomever or whatever is responsible please forward our thanks and appreciation. My husband's stage 4 colon cancer is currently in a "guarded" remission. Two of the three lesions are not longer visible via the latest PET scan. He is still taking chemotherapy but not quite as strong as during the first 7 months. Life is good and we are blessed.

Your assistance has indeed lightened our financial burden and we both are forever grateful. My husband is now the recipient of social security disability and I still work full time. Our financial picture is much better and we may not qualify for your help in the future but you sure helped us when we needed it most.

I am sure that you have helped so many others and I hope that the funding will continue to help others in the future.





Joseph Bossette, Non Muscle Invasive Bladder Cancer Houston, TX

I really really feel like my wife and I know you. We thank you and appreciate everything you are helping us with and for not making it so complicated. Most of us seniors just give up because we don't know which way to go or who to ask and most of us don't ask because we have been turned away so many times so most of us feel "Oh well, this is it for me". But when we meet people like you, it restores one's faith and you say to yourself, 'maybe I can go on a little bit longer because there is some out there who really does care'. So again, thanks. We are blessed to have you and you're blessed for helping us.

How do you measure a year? As Patient Advocate Foundation (PAF) looks back over the fiscal year of July 1, 2011 to June 30, 2012, this Annual Report will reflect on how PAF's programs and services provided much needed assistance to patients diagnosed with a chronic, life threatening and/or debilitating disease. The measure for us is how the assistance provided eased the journey that our patients endured and resolved their healthcare access problems. Five hundred twenty-five thousand six hundred minutes.....

FY 2011/2012 Patient Services Division Summary **Summary of Patient Cases and Contacts** 

Case Count:	87,404
Total Email Contacts For Direct Patient Services:	40,404
Total Patient Case Count:	127,808
Case Contacts:	1,418,219

Patient Advocate Foundation celebrated its 16th year of operations, having opened its doors on April 4, 1996 as a national 501(c)3 non-profit organization. Its mission has remained the same throughout those 16 years:

"safeguarding patients through effective mediation assuring access to care, maintenance of employment and preservation of their financial stability." PAF serves as an active liaison between 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 health care attorneys.

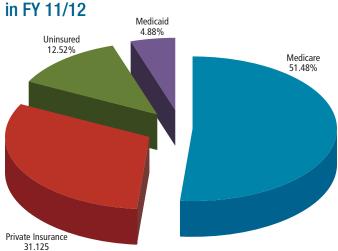
PAF provides numerous programs and services, has partnerships with other national non-profit organizations and is routinely recognized nationally as the leading patient advocacy organization. FY 2011/2012 brought with it many highlights throughout the year.

Patient Advocate Foundation began FY 2011/2012 with a comprehensive review of the operations of our **Co-Pay Relief (CPR)** program in order to determine if our model was still viable in today's marketplace. Our model worked very well at inception of the program, but as the number of disease silos increased, as well as the number of patients seeking co-payment assistance, the model had become burdensome and not patient or provider friendly. In August of 2011, PAF launched a completely new model for Co-Pay Relief, one that eased the way for patients and providers to apply for assistance as well as cutting-edge technology enhancements. It also allowed CPR to provide even better customer service to our patients and their providers and pharmacies.



### **Doan-Trang Nguyen, Breast Cancer** Chantilly, VA

The calls and emails were immediate. The counselor was very kind and informative. We did not come to PAF first but as soon as we did, the major parts of our worries were over and you are like the Rocket Boosters of the world most advanced traveling system since the dawn of time.



# Insurance Coverage Reported by PAF Patients in FY 11/12

available and all documents will be automatically attached to an application by the system when uploaded and/or faxed. All of these enhancements allow the CPR program to better assist patients when applying for co-payment assistance for their life-saving medications.

Once the review was completed, implementation of the changes began in August, 2011. The most significant change was how PAF handles donations to the program. All donations are now released in full the first month that they are received. We accept new and renewal applications on a first come, first serve basis with no limit imposed each month on the number of approvals issued. Thirty-three percent of the grant award is reserved for the patient with the remaining 67% of their award available on a first come, first served basis. Patients with no activity within their account for over 120 days, will have their account closed and the funds will be reallocated back into the appropriate disease silo. All expenditures, with the exception of the reserve amount, are accepted and processed on a first come, first serve basis until such time that the available funds in the silo are exhausted.

In addition to the way in which funds are handled, PAF CPR implemented enhanced technologies to expedite completion of the application process. Those technologies include E-signature capabilities within the online application process at all points where a signature is now required. Patients, providers and pharmacists will now have the capability of importing documents as part of the online application process either directly or through eFax. Bar code recognition for faxed documents will be available for those users who do not have electronic documents

### Jackie Douglas, Colorectal Cancer Gray, LA

I would like to say "THANK YOU" from the depths of my heart. When I was diagnosed with colon cancer, it felt like my heart stopped beating. There was confusion, the questioning God why, the bitterness and anger. It emotionally crushed me and the thought of not knowing how to tell this to my family, my kids, how was I going to deal with this issue and the medical bills that would stack up against me. I had no idea where to turn for support or help. There was concern of when my medical insurance will reach its limit, how would I continue to do my treatments and pay for them. When the advocate from our local Council on Aging talked with me and explained to me that we could try to apply for assistance thru the Patient Advocate Foundation Co-Pay Relief, I was encouraged and once I received the information from you that I was qualified for the assistance, my heart rejoiced within. You gave me hope in the midst of my doubting. I am still struggling financially, but knowing that there is some sort of help makes me feel better even on my bad days. My faith will continue to be strong in the Lord and my spirts high. I can't thank you enough for your support, you are truly heaven sent.

PATIENT ADVOCATE FOUNDATION CO-PAY RELEEF A Patient Assistance Program

In FY 2011/2012, **Co-Pay Relief** program experienced a 168.4% increase in the number of patients served, moving from 13,781 patients in FY 2010/2011 to 36,993 patients. PAF also received word in August from Kantar Health, a national research and consulting organization that provides information to the pharmaceutical and biotechnology industry, that as a result of a survey to oncologists and practice managers, the Patient Advocate Foundation's Co-Pay Relief program had been rated Number One in the nation for service and ease of use of the program.

Additional Co-Pay Relief Highlights for FY 2011/2012:

- In FY10/11CPR expended \$18,733,160.58 and in FY11/12 CPR expended \$39,612,785.76, an increase of 111.5%.
- The program experienced a 10.9% increase in the number of expenditures processed in FY11/12, totaling 49,531 individual payments on behalf of patients
- The CPR Program has successfully completed 8 years of operations allocating more than \$170,137,000.00 in patient assistance, a 30.3% increase from last fiscal year.
- CPR opened the Non Muscle Invasive Bladder Cancer, Hormone Suppression Therapy and Electrolyte Imbalance silos. CPR also split Chemotherapy Induced Anemia/Chemotherapy Induced Neutropenia into two separate silos.

Patient Advocate Foundation would like to thank the following donors for their continued financial support of the Co-Pay Relief Program in FY 2011/2012:

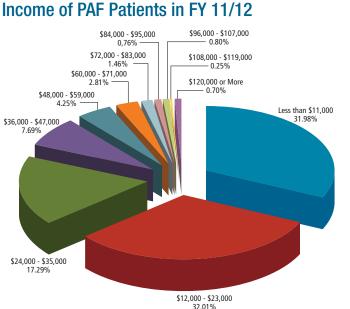




Patient Advocate Foundation expanded the Virginia Cares for the Uninsured Program (VCUP) with funding received from the Obici Foundation, based in Suffolk, VA. VCUP was implemented in 2007 and continues to assist uninsured or underinsured Virginians, through free sustained direct case management services to patients who have been diagnosed with a chronic, debilitating, or life-threatening illness and are experiencing access to health care issues. The Obici funding provided case management and outreach to patients living in Suffolk, Franklin, Isle of Wight, Southampton, Surry and Sussex counties in Virginia and Gates County, North Carolina. VCUP case managers completed 186 outreaches during this period reaching 4,344 attendees.

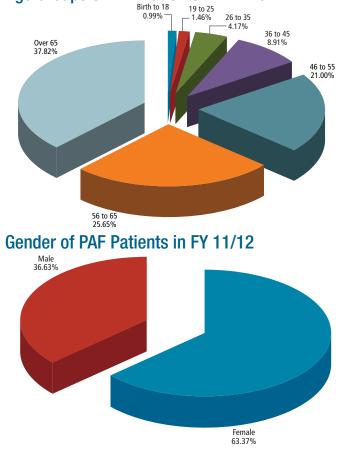


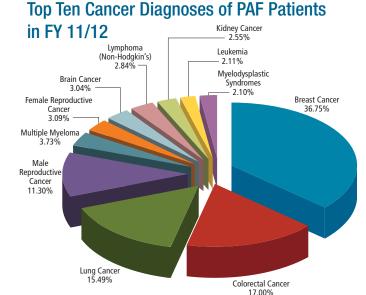
PAF also entered into a second year of partnership with **Cancer Treatment Centers of America (CTCA)** to provide sustained case management services with an emphasis on Medicare and uninsured patients who were seeking care at CTCA medical facilities and were experiencing access to care issues. The obstacles included insurance issues and inability to afford out-of-pocket expenses. Through the partnership, these patients were referred directly to PAF for assistance. The program features a dedicated 1-800 phone line, secure web based provider referral portal and dedicated case management staff. The CTCA team assisted 943 patients and successfully obtained \$546,712.69 in medical debt relief for patients.



VCUP successfully resolved 1,951 patient cases through direct arbitration, mediation and negotiation, obtaining \$2,144,188.44 in medical debt relief. The OBICI VCUP team assisted 351 patients and successfully obtained \$325,610.33 in medical debt relief.

### Age Groups of PAF Patients in FY 11/12





In August, PAF entered into the fifth and final year

of its cooperative agreement with the Centers for Disease Control and Prevention (CDC). The Early Detection and Survivorship of Cancer in Underserved Populations (SCUP) goal is to increase survivorship of cancer and enhance the quality of life in the underserved population by providing direct case management services to patients with breast, cervical, ovarian, colorectal, prostate and skin cancers. PAF provides outreach and education to increase awareness of our services available to the uninsured, underinsured, minority and disparate populations. We have met all of the goals set forth in the work plan submitted to CDC and have received excellent feedback in regards to the data available in the last reporting period. A key component is not only case management but educational outreach provided to healthcare providers. This is through PowerPoint presentations or small group meetings with the staff of healthcare providers that would make a referral to PAF. The outreach planned for this time period included a Midwest Swing through Nebraska, Kansas and Missouri. The Program Director for this grant lives in the state of lowa and included outreach in the state as well as attending the first ever African American Breast Health Summit in March and PAF exhibited at this conference. South Dakota outreach activities

included a webinar to the Breast and Cervical Cancer

Prevention Program.

The outreach efforts in all five states in the Midwest were successful because of the communication with the state Cancer Coalitions who helped in making the contacts with the healthcare providers that would benefit from hearing about PAF Patient Services. CDC promoted PAF services by providing an opportunity to conduct a webinar in May with Tribal Programs across the United States. This included 7 Comprehensive Cancer Control, 11 Breast and Cervical Cancer and 4 Colorectal Cancer Tribal Programs. Eight states are represented by tribal or territory programs including: Alabama, Arkansas, Arizona, Minnesota, South Dakota, Oklahoma, Oregon and Washington.

The number of patients served under this grant during the time period was 3,884. Patients contacting PAF under the SCUP grant report debt crisis as the number one issue. PAF is able to report for this time period that fees recovered totaled over \$3,232,579.00 including charitable contributions to help with living expenses and with cancer treatment in the form of financial assistance to health care providers and/or write off amounts from the provider to the patient to help alleviate the stress of financial responsibilities.

SCUP team members attended Ovarian Cancer National Alliance Annual Conference, Association of Oncology Nurse Navigator Conference, National Coalition of Oncology Nurse Navigators, San Antonio Breast Cancer Symposium, C4YW-Conference for Young Women Affected by Breast Cancer, National Association of Black Social Workers.

**Jeffrey Pounds, Liver Cancer** Cedar Park, TX

Your Patient Advocate program is a life saver to me. Thank God for beautiful people like Brendan Bietry and all of the PAF staff. Please never stop helping because you're all incredible. I will continue to tell everybody I can about how blessed I am to have PAF on my side. PAF has saved my life.

### The National African American Outreach

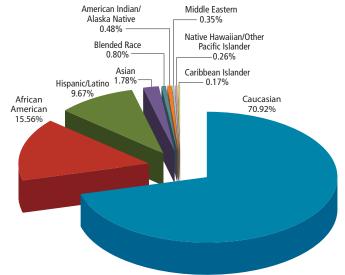
**Program (NAAOP)** is a disparity program at PAF designed to target African American patients at local, regional and national events and to increase awareness about PAF case management services. NAAOP's mission is to help reduce health care disparities and assist clients in obtaining a better quality of life within disenfranchised communities by disseminating PAF educational materials.

During FY 2011/2012 NAAOP participated in or was represented through other PAF programs at 212 events reaching out to over 16,732 attendees who were made aware of PAF services. During the year NAAOP provided case management services to 5,002 patients. Our 2011 Patient Data Analysis Report (PDAR) showed that 18% of PAF patients served were African American which is an increase of 1.09 percentage points from the 2010 PDAR in which 16.91% were African American. Some of the major events the NAAOP members provided outreach to were: The National Black Nurses Association Annual Conference in Indianapolis, IN (1200 attendees), Victory Over Diabetes in Washington, DC (500 attendees), Field of Friends in Newport News, VA (700 attendees), National Association of Black

Social Workers in Atlanta, GA (600 attendees), 34th Annual Black Family Conference in Hampton, VA (300 attendees) and the Director, Carolyn Andrews, LPN was a speaker for the American Diabetes Association-AA initiative meeting in Alexandria, VA. Quotes from African American Patients Served by PAF Case Managers: "My case manager was very thorough and clear on explaining what I needed to know and do about my issues. She was very polite and patient"

"The person I spoke to answered all of my questions and was very helpful in assisting me on what I needed. I will tell whoever needs help to contact PAF. Thank you so much"

### Ethnicity of PAF Patients in FY 11/12





### Kayla Whitely for patient, John Lott, Small Cell Lung Cancer Douglas, GA

I just want to say "thank you" for the help you have provided me with my Daddy. It is so hard sometimes to ask for help but when someone makes it so it is not a handout it makes it so much easier. Ms. Carlette was so easy to talk to and made me feel better about not being able to do everything on my own and letting me know that it is okay to need help. She had so much information to give me about this disease and places that could possibly help our family. I am so thankful that there are

people like Ms. Carlette and organizations like the Patient Advocate Foundation that are here when families like mine need it. Thank you from the bottom of my heart.

#### Health Conditions of PAF Patients in FY 11/12 Nervous System **Pediatric Conditions** Conditions 0 49% 1.19% Kidney Diseases Screening for Symptoms 1.50% 0.40% Cardiovascular Organ Transplantation Conditions 0.13% Autoimmune 1.59% Diseases Cancers 15.67% 61.60% Chronic and/or Debilitating Condition 17.43%

The National Hispanic/Latino Outreach Program (NHLOP) team continues to provide presentations to agencies and medical facilities as a result of the establishment of the district office in San Antonio, TX with bilingual case managers. NHLOP conducted 144 outreaches in California, New York, Virginia and Texas during FY 2011/2012, distributing over 2,600 publications and included:

- Live Strong Assembly as a member of the Hispanic/Latino Advisory Committee
- Presentation to the National Association of Puerto Rican Social Workers
- Nueva Vida Zumbathon & Health Fair
- County of San Diego Health and Human
  Services
- National Council of La Raza-Family Expo



Patient Advocate Foundation and the American

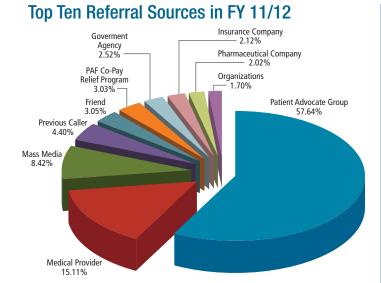
**Cancer Society (ACS)** completed their fourth year of formal partnership in FY 2011/2012. Our professional case managers continued to provide the full range of PAF services to ACS referred patients every day. This past year PAF established a separate, direct telephone line for ACS patients to ensure that all referrals received timely response. With the addition

# **Chronic or Debilitating Conditions**

Addison's Disease Adrenal insufficiency ALS (Lou Gehrig's Disease) Amputations Amyloidosis Anemia Aplastic Anemia Asthma Bladder dysfunction Blindness Blood Disorder Bronchitis Chemo-induced nausea and vomiting Chemo-induced neutropenia Cirrhosis **Clotting Disorder Connective Tissue Disorders** COPD (Lung disease) Cushing's Syndrome Degenerative Disc Disease **Degenerative Joint Disease** Devic's Disease **Diabetes Insipidus** Emphysema FAP (Familial adenomatous polyposis) Fasciitis Fibromatosis Fibromyalgia Gauchers' Disease Glaucoma Hemochromatosis Hemolytic Anemia Hemophagocytic Lymphohistiocytosis Hemophilia Hepatitis Hereditary Hemorrhagic Telangiectasis Histiocytosis Histoplasmosis HIV/AIDS Huntington's Disease

Hydradendritis Hyper/Hypothyroidism Hypogammaglobulinemia Hypopituitarism Immune Defiency Disorder Infectious Disease Kearns Sayre Syndrome Leukodystrophy Liver Failure Lymphadenopathy Lymphedema Macular Degeneration Meningitis Monoclonal gammopathy **Myelofibrosis** Neuropathy Non-healing Chronic Ulcer Osteomyelitis Osteonecrosis Osteoporosis Pancreatitis Paralysis Parathyroid disorder Peripheral Neuropathy Polio Polycythemia Vera Polymyositis **Protein Deficiency** Pulmonary Disease Pulmonary Emboli Pulmonary Fibrosis PXE (Pseudoxanthoma Elasticum) Pyoderma Gangrenosum Short Bowel Syndrome Sickle Cell Anemia Syringomyelia Thrombocytopenia Thyroid Disorder TTP Tuberculosis Venous Occlusive Disease Vision impairment Wilson Disease

of more bilingual Medical Intake Specialists, PAF was able to provide the same live response service to our Spanish speaking callers as English speaking patients received. Cases were also received though the secure web based patient portal, allowing ACS call counselors and navigators the ability to refer cases at any time of the day or night.



Patient Advocate Foundation received 7,840 patient referrals from the American Cancer Society. Of those referrals, 5,447 patients were served under the ACS grant. An additional 2,393 patients that were referred by ACS were served by other programs better suited to their needs, including our CDC SCUP, the Virginia Cares for the Uninsured Program (VCUP) or the MedCareLine.

"I am writing this letter to thank you for assistance in negotiating with my bills. I would also like to thank you for all the referrals. There referrals are turning out to be very helpful. I am very grateful for all your help. I will highly recommend your services to anyone else in this situation." Lori B., OH Kenneth Horsford, Stage 4 Prostate Cancer East Orange, NJ

I would like to thank you from the bottom of my heart and I appreciate all that you have done for me. I had never heard about Patient Advocate until I picked up the phone and called that 1 800 number. I have no regrets whatsoever. The people I spoke to were so helpful, so caring, polite and understanding. They were able to solve my problem in the best possible way they can. Now I am able to relax and enjoy my life. Thank you Patient Advocate. Keep up the good work. God bless you.

As a result of the success of the national partnership between PAF and ACS, our services were able to expand to assist one of the ACS divisions. In December the **ACS East Central Division** and Patient Advocate Foundation entered into an agreement to provide case management services to breast cancer patients residing in Ohio and Pennsylvania who have been referred by ACS representatives for assistance. Patients in rural areas were especially targeted for PAF case management services under this agreement. We have assisted 183 patients since the inception of the program.

### Martha S. Petit, M.Ed, Ed.S

Peninsula Cancer Institute and Riverside Cancer Infusion Center Williamsburg, Newport News and Gloucester, VA

"I would like to thank the Patient Advocate Foundation for providing excellent support to the Cancer Survivors in our community. The Cancer Survivors we assist in our clinic have multi-faceted needs – everything from trying to stay on top of payment for their medical bills and medications to returning to work after treatment. I often wonder if the stress of the monetary mountain they see before them isn't more of an obstacle to wellness than the disease itself. The staff from the Patient Advocate Foundation has stepped up to provide excellent information and support to all involved, including those of us who assist the patients and families with their journey in the world of cancer. It has been said, information is power. To give power to and to support those who are seeking answers, whether they seek out of need or of fear, is a noble cause. And it is for these many acts of empowerment, I wish to express my gratitude."

### LIVESTRONG

In kicking off the calendar year of 2012, PAF celebrated 8 years of partnership with LIVESTRONG, having been one of the original partners in the program originally called SurvivorCare. FY 2011/2012 saw the addition of another Spanish speaking case manager to the LIVESTRONG core team and being housed in our San Antonio, TX office. Additional highlights include:

- PAF attended the LIVESTRONG assembly in Austin, TX
- PAF continues to sit on the LIVESTRONG National Hispanic Outreach Advisory Board to assist with all aspects of the LIVESTRONG National Hispanic/Latino initiative
- LIVESTRONG partners attend monthly conference calls updating all partners with services provided, new initiatives and feedback on processes
- PAF provides a patient success story to LIVESTRONG monthly which is posted on the LAF BaseCamp website
- Warm call transfers option for LIVESTRONG patients being referred from their call center in Austin continues to be an asset in immediately being able to assist patients
- The PAF/LAF core case management team served 4,827 patients during this year

Additionally, PAF entered into its second year of partnership, through which a PAF Senior Case Manager is housed on site in the LIVESTRONG Cancer Navigation Center in Austin, TX. Brendan Bietry, the case manager, was able to provide faceto-face case management services to 583 patients during this fiscal year.

Patient Advocate Foundation and Susan G. Komen



for the Cure expanded its collaboration and partnership in March. Komen has been a partner in our Co-Pay Relief

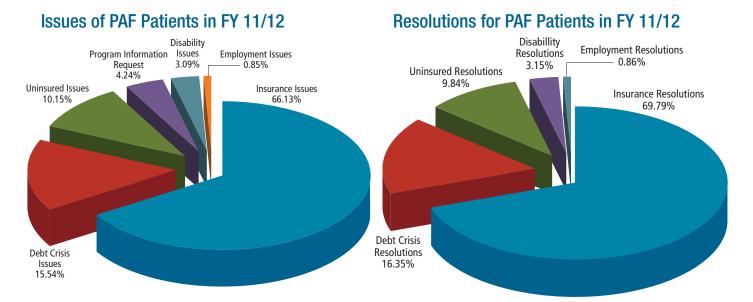
program since 2006, providing funding for our breast

cancer silo. In FY 2011/2012, Komen made a two year commitment to our CPR program and also provided funding for PAF to coordinate outreach to African American and Hispanic/Latina women who have been newly diagnosed with breast cancer and might be in need of co-payment assistance in order to receive their medications.

Outreach provided information about PAF case management services as well how to enroll in the CPR program. The outreaches were conducted by members of our National African American Outreach Program (NAAOP) and our National Hispanic Latino Outreach Program (NHLOP) and consisted of one weeklong visits to:

- Atlanta, GA
- Washington, DC
- Chicago, IL
- Philadelphia, PA
- Dallas/Houston/San Antonio, TX
- Los Angeles/Orange County, San Bernardino/ Riverside County/San Diego, CA
- New York, NY

For FY 2011/2012, PAF conducted 275 visits and appointments, and distributed over 10,300 brochures and publications. Two of the PAF publications, "Promoting a Healthier African American Community" and "Promoting a Healthier Hispanic/Latino Community" were updated and revised, specifically adding information on the Breast and Cervical Cancer Program with contact information and statistical information related to African American and Hispanic/ Latina women. PAF also conducted a webinar for Susan G. Komen for the Cure and 250 of its affiliates which focused on the changes that had been made to PAF's Co-Pay Relief program as well as PAF case management services. It was the largest webinar attendance in the history of Susan G. Komen for the Cure.



### **Insurance Issues Include:**

- Co-pay, premium and/or deductable assistance
- General benefit questions
- Requesting assistance with facilitating a second opinion
- Inability to afford Medicare Part D cost share
- Benefit exclusion
- Claims denied due to not medically necessary
- Medicare Part D coverage issue
- Inadequate coverage options/underinsured
- Coding and billing errors
- Request for guidance with eligibility or enrollment in PCIP

### **Debt Crisis Issues Include:**

- · Inability to afford transportation
- Inability to afford rent/mortgage
- Inability to afford utility/shut off notice
- Inability to afford food/nutritional needs
- Inability to afford non-covered supplies
- Inability to afford lodging expenses
- · Inability to afford commodities/home adaptation
- Inability to afford car note/car insurance/car repair
- Inability to afford burial/funeral expenses
- Facing eviction/foreclosure

### **Insurance Resolutions Include:**

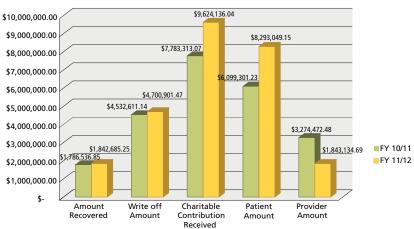
- Faciliated/obtained co-pay, premium and/or deductable assistance
- Educated on general benefit questions
- Faciliated/obtained charity care for underinsured
- Facilitated/obtained/offset cost through alternative assistance
- Enrolled into pharmaceutical indigent drug program
- Negotiation of payment plan/discount for patient
- Medicare Part D coverage issue resolved
- Interpreted second opinion via plan language
- Enrolled into Medicare extra help/closing share of cost
- Facilitated/obtained medical assistance (DME)

### **Debt Crisis Resolutions Include:**

- Facilitated/secured free or charity for transportation assistance
- Facilitated/located food assistance
- Facilitated utility/phone relief
- · Facilitated rental/mortgage payment relief
- Offset cost through alternative assistance
- Facilitated/located needed supplies
- Facilitated/negotiated free, reduced rate, or charity for lodging assistance
- Facilitated/located commodities/home adaptation

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PAF was able to obtain debt relief for patients in FY 2011/2012 in the amount of \$26,303,906.60. This amount includes only the financial relief that is reported to case managers and/or recovered during the course of our work with an open case. The debt relief breakdown is:



### Debt Relief Obtained for PAF Patients in FY 11/12

Total Debt Relief\* Obtained: \$26,303,906.60

\* Case managers can only document financial relief that is reported and/or recovered during the course of our work with an open case. Any long term or future financial benefits resulting from resolutions are not captured.

Amount Recovered:	\$1,842,685.25
Write Off Amount:	\$4,700,901.47
Charitable Contribution Received:	\$9,624,136.04
Patient Amount:	\$8,293,049.15
Provider Amount:	\$1,843,134.69

- Amount Recovered: the amount PAF recovered from third party payers such as commercial insurance plans and Medicaid or Medicare programs.
- Write off Amount: the amount of patient debt relief obtained by PAF through negotiations with facilities and/or medical providers.
- Charitable Contributions: the amount PAF secured on behalf of patients through utilization of national and/or local charitable resources such as hospital charity care programs, non-profit financial aid programs and/or local faith or disease based programs.
- Patient Amount: the amount directly returned to patients as a result of PAF negotiating reimbursement for out of pocket medical expenses.

• Provider Amount: the amount directly returned to providers as a result of PAF negotiating reimbursement for medical debt that had been previously written off or logged by the facility as "uncollected".



### ACCESS TO EMERGING MEDICATION THERAPIES

PAF also celebrated six years of serving patients through the MedCareLine Division. The **MedCareLine** is a patient/provider hotline designed to assist patients who are seeking education and access to emerging therapies and treatments and who have been diagnosed with a particular disease. The **Colorectal CareLine** was the first CareLine created and its goal is to assist patients who have a diagnosis of colorectal cancer and are in need of PAF's sustained case management services. In FY 2011/2012, the Colorectal CareLine assisted 1,894 patients. At the end of the fiscal year, PAF began the creation of the **Narcolepsy CareLine** to assist patients with a narcolepsy diagnosis.



**Breakaway from Cancer (BFC),** a component of The Amgen Tour of California (AToC) was held May 13-20, 2012 and included the following stages:

- Stage 1: Santa Rosa to Santa Rosa
- Stage 2: San Francisco to Santa Cruz County
- Stage 3: San Jose to Livermore
- Stage 4: Sonora to Clovis
- Stage 5: Bakersfield to Bakersfield
- Stage 6: Palmdale to Big Bear Lake
- Stage 7: Ontario to Mt. Baldy
- Stage 8: Beverly Hills to Los Angeles

Stages 1, 3, 4 and 8 were designated as Breakaway from Cancer stages. Breakaway from Cancer is a national fundraising and educational initiative founded by Amgen in 2005 as a component to their sponsorship of the Amgen Tour of California, a world class professional cycling competition. Breakaway from Cancer was created to raise awareness of the resources available for cancer patients, covering the spectrum of prevention, fighting cancer, financial assistance and survivorship. The four partner organizations are Prevent Cancer Foundation, Cancer Support Community, Patient Advocate Foundation and the National Coalition for Cancer Survivorship. This is the fourth year that PAF has been a partner in the initiative.

Millions of Americans benefit from the resources that are available from the four partner organizations that work collaboratively with the BFC initiative. Those resources help patients navigate the continuum of cancer care from prevention to survivorship. At each stage of the event, a BFC Festival Tent joins other vendors and the four partner organizations are able

to educate attendees on the services provided by their organizations. Jamilla Williams, PAF Regional Case Management Director and Brendan Bietry, PAF LIVESTRONG Senior Case Manager attended all eight stages, educating thousands of attendees on PAF services. Nancy Davenport-Ennis, PAF CEO and Jack Ennis, PAF Chief Development Officer attended the PAF stage in Santa Rosa, leading the Breakaway Mile, a one mile celebratory walk for cancer survivors, patients, caregivers and family members to lead the way in breaking away from cancer. During the walk, a cancer survivor, advocate or caregiver who has actively made a difference within their community is designated as the Breakaway from Cancer Champion. PAF was able to nominate six candidates to be recognized.

BFC is not just the event in California. Throughout the year, PAF asks patients calling in for assistance if they are aware of BFC and its purpose and the resources it provides. For FY 2011/2012, PAF staff educated 18,181 callers who previously were unaware of BFC and the resources available through the BFC Partners. There were an additional 1,273 callers who had previous knowledge of BFC.

#### Patricia Holman, Asthma Walnut Cove, NC

I was very pleased with the assistance I received from the Patient Advocate Foundation. They gave me concise, informative materials each time I spoke with them. They made calls for me. They sent me updated information. They were always pleasant and kind on the phone while being professional. They always returned my calls if message left. Most important was always having an uplifting word, never a put down with every call. Sometimes that is the only thing you need to hear to make your day. Just knowing that someone out there had time to listen and not be judgmental. I will always count Tracey in my heart and in my prayers.

### The Patient Action Council (PAC)

which was created in 2009, unveiled its newest product for patients: The National Uninsured Resource Directory. The goal of PAC is to provide a forum for pharmaceutical/ biotechnology industry patient advocacy leaders to collaborate with PAF leadership to address one major health care access issue. Past deliverables have been the National Underinsured Resource Directory and the website www. insureUStoday.org. The 2011/2012 deliverable, the National Uninsured Resource Directory mirrors the National Underinsured Resource Directory by providing an interactive, dynamic web-based resource guide that is publicly available. Patients are able to visit the site and obtain resource information for their particular issues. Members of the

NATIONAL <u>UN</u>insured RESOURCE DIRECTORY



FIND THE MISSING PIECES Patient Action Council include:

- Kathryn West, Advocacy Director, Oncology, Amgen
- Cara Thompson, Director, Advocacy, Celgene
- Meredith Burgents, Director, Global Advocacy and Professional Relations, Oncology, Eli Lilly
- Fran Kochman, Director, State Government Affairs, GlaxoSmithKline
- Alissa Jaffe Nagler, Director, Patient Access Patient Advocacy and External Affairs, Novartis
- Patti Jewell, Director, Worldwide Alliance Development, Pfizer Oncology
- Kesslyn Smith, Director, North America Corporate Social Responsibility, Sanofi, US



### Jocelyn Roderamel, Stage 4 Breast Cancer Hamilton, VA

Until we found ourselves dealing with Cancer personally and trying to handle the financial strain that has come with it, we had no idea how many people and organizations such as yours really do care and do what they can to help relieve some of the fears and concerns that accompany this disease.

We so much appreciate your help in leading us to possible financial

assistance. The Cancer, the situation and its strain on all of us can be so very overwhelming and you definitely helped to relieve that by guiding us through and to more help. We did not have the neither energy nor time to research and pursue the needed information. Your representative, Michelle, was so caring, prepared and helpful with clear instructions that the stress was being relieved immediately upon the call! The follow-up letter in addition helped us to be sure we had done all that we needed to from our end.

Your understanding and caring at a time like this is cherished. We thank you so very much and will be happy to recommend your help to others.

# OPERATIONAL ENHANCEMENTS

### The PAF Employee Relations Committee (ERC)

planned numerous events for PAF staff throughout the year. In August, PAF celebrated Spirit Week where each day brought a different theme:

- Maui Monday-Dress in your best Hawaiian attire
- Twin Tuesday-Pick a friend to be your twin
- Wacky Wednesday-Wear your wackiest, tackiest outfit
- Throwback Thursday-Dress fine to represent any decade in time
- Foundation Friday-Blue and yellow (PAF colors) is the theme, representing as a team.

The ERC also provided staff with the opportunity in October to show support for the various cancer awareness days that occur in October, the most recognizable one being for breast cancer. Staff was asked to wear pink on a designated Friday to show their honor for those who have survived a breast cancer diagnosis as well as to honor the memory of those who passed away from their disease.

November brought about a **Food Drive for the Virginia Peninsula Food Bank**, continuing a tradition that started several years ago. This year, donations totaled 2,633 pounds of food to be distributed to needy families in the Hampton Roads area.

















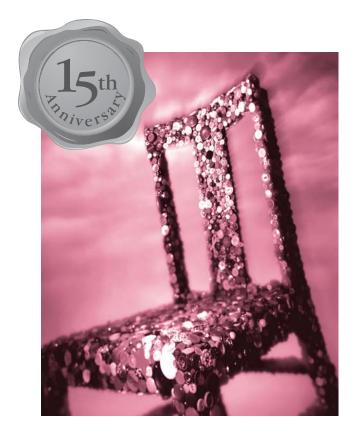


William Slater, Breast Cancer Ingleside, TX

Thank you for your help. There is no way I could pay for this chemo because I am retired on disability. I make a little too much for Medicaid. I can't get Medicare Part B because I am not 65. You have a very high class organization. I have already recommended your organization. God bless you all.

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#### PATIENT ADVOCATE FOUNDATION | ANNUAL REPORT 2011/2012



On December 6, 2011, Patient Advocate Foundation hosted an Open House to celebrate our 15 years of providing assistance to patients in need. Our guests had the opportunity to tour our facility and interact with our staff. In addition, the event featured the interactive "Button Chair" exhibit, a project of the Blue Cross and Blue Shield of North Carolina (BCBSNC) Foundation. The Button Chair was created in 1998 and is designed to increase awareness of breast cancer in hopes of saving lives. Every button on the chair represents a story of courage and strength as each button once belonged to a breast cancer survivor or to someone who lost their battle to the disease. Exhibiting the Button Chair during our Open House was also one of the few times the Button Chair has been out of North Carolina.

PAF received notification in January, 2012 that *MainStreet*, a blog site on MSN Money, had reviewed the Charity Navigator ranking of the 5,500

charities it ranks. There were 238 that received perfect 4 star ratings, PAF being one of them. *MainStreet* filtered out the organizations that operate only locally and those that mainly collected and distributed funds to other charitable organizations (ie: United Way). Patient Advocate Foundation, with a Charity Navigator score of 69.40 (out of 70) ranked number two on that new ranking list, coming in second to an organization that provides vacations for terminally ill children to Florida's famous theme parks.



Also, in May, PAF received notification from **Charity Navigator**, America's premier charity ranking organization, that we were in receipt of our third consecutive 4-Star rating. Only 9% of all charities receive 4-Stars three times in a row. Charity Navigator's goal is to help guide donors to charities that they can donate to with confidence that their donation is going to a viable organization. They rate charities by evaluating two areas of performance: Financial Health and Accountability and Transparency.

Financial health is evaluated by the information provided on IRS Form 990, a charity's tax return. Seven key areas are evaluated to assess the charity's financial performance and its financial efficiency and financial capacity. Accountability and Transparency is evaluated through additional information on the Form 990 as well as information that is provided through an organization's website.

Throughout the FY 2011/2012, Patient Advocate Foundation has been featured as a trusted source for patients in numerous tier one and tier two media outlets. These include both print and broadcast sources:

Health MAGA: The Health Magazine Kaiser Health News K104.7 Radio-Charlotte, NC Fox Business News AARP Bulletin Today Sacramento Bee Pittsburgh Tribune-Review Florida Sun Sentinel Cancer Today CNN Health Biloxi Sun-Herald The Huffington Post

# Los Angeles Times Ehe New york Times

# The Washington Post

# The Virginian-Pilot Guardian Express



**Richmond Eimes-Dispatch** 

SeniorJournal.com The Dallas Morning News

**The Detroit News** 

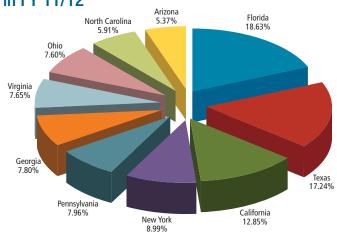
msn

**Smart Money** 

THE ARIZONA REPUBLIC HemOnc today<sup>\*</sup> Daily Press THE WALL STREET JOURNAL.



# Top Ten Referral States for PAF Patients in FY 11/12



### Blog sites include:

Cancer Support Community blog Leukemia & Lymphoma Society of Canada blog 1 Up on Cancer blog MSN Health MainStreet by Money Talks News The Hill-Congress blog AOL News' Daily Finance Bright Hub blog NPR blog Dr. Health and Wellness blog Health Insurance Providers blog Cancer Kick blog HealthInsurance.org Dead Man Skipping blog

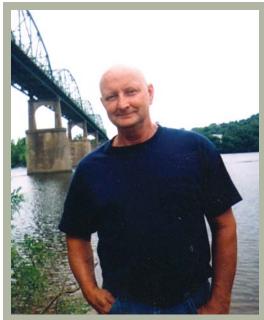
Patients, providers, caregivers, and government representatives learn about PAF and our services not only from the articles and blog postings that feature PAF but also through visiting our numerous websites. In FY 2011/2012, PAF received 40,404 emails from someone needing assistance and sent over 95,000 messages to subscribed email users. Patient Advocate Foundation also maintains many websites for various programs as detailed in the breakdown of unique visitors, page views and average amount of time spent on each site:

Website	Unique Visitors	Page Views	Average Time
www.patientadvocate.org	262,231	1,057,249	2.30 minutes
www.copays.org	133,276	914,122	2:55 minutes
www.napf.org	20,772	82,844	2:14 minutes
www.colorectalcareline.org	4,477	19,030	1:54 minutes
www.pafcares.org	3,257	7,618	1:43 minutes
www.promiseofhope.net	2,407	10,816	2:55 minutes

### Stacy Remy, Osteosarcoma

Huntersville, NC

PAF, you are very professional and yet warm and caring at the same time. You are solutionsoriented, courteous, helpful and informative including follow-up which provided me with additional resources to continue in our journey through this process. The fact that the people I spoke to had been (unfortunately) touched by cancer in some way too adds a depth and understanding too, that I appreciate.



### **Linda Harold for patient Edward Keith Harold, Malignant Brain Tumor** Philadelphia, TN

Gayle was a 'big' help getting things back on track. It means a lot to us. While Keith was in the hospital, they signed him up for disability. It didn't start until September 2011. Thank God for it but he doesn't draw enough to pay the bills. We do what we can. When he worked, he made more in two weeks than what he draws now. You know God has been so good to us through all we have been through. Keith is a Vet. When we signed up for disability, Social Security told us we had to sign up to see if we could get some help from the VA. So we did. It took a while. So again Gayle, "thank you" so much for helping me make all those phone calls.



# **A LETTER FROM THE PRESIDENT, OPERATIONS** Fran Castellow, MSEd.

Dear Friends,

It is hard to remember a year that challenged our nation more than 2012. This year has proven to be one of continued financial hardship for many with record setting unemployment rates, downgrading of our nations credit, continued war in the Middle East, natural disasters that have decimated homes and businesses, the looming "fiscal cliff" and the erosion of the citizenry's confidence in our government's leadership. People are suffering in ways we could not have imagined and there are little to no safety nets to catch them any longer as public resources continue to be cut back. The families PAF had the pleasure to serve this year were not only impacted by the state of the nation's economy but were also dealing with a personal family crisis as they managed the issues of a life threatening and/or debilitating diagnosis. Over 127,000 people arrived at our doors this year experiencing financial and practical issues that were impeding their access to the very healthcare that they needed the most. We saw firsthand the financial devastation families experienced when a loved one fell quickly and tragically ill and it is almost unexplainable to those who have not lived the journey.

Despite the often bleak and harsh reality that many people face daily there is an unexplainable, undeniable sense of faith that has emerged. **Faith, quite literally, is defined as the belief in, devotion to, or trust in somebody or something, especially without logical proof.** Our patients, and their families, have faith that is infectious. Faith that they will be at their disease. Faith that they will be able to continue to care for and love their families. Faith that they will celebrate another Christmas, birthday, and enjoy another set of seasons. Faith that we, PAF and our wildly committed team of professionals, will solve their financial and practical issues so that they can focus on getting well without the worry they came to us with. It is this faith that motivates us to be our best, never give up and find solutions to each patient's issues as if they were our own family. Our staff is committed to maintaining the faith and confidence our patients and their families have in PAF and our services. We offer our compassion, competent navigation of the healthcare delivery and reimbursements systems, direct financial support, and professional guidance all of which are required to resolve cost of living and access issues our patients face. Most importantly, we deliver reciprocal faith to our patients and their families that together, we will bring a sliver of peace and calm to an otherwise tumultuous environment.

In FY2011/2012, PAF had the opportunity to work with and on behalf of more than 127,000 patients nationwide. We were successful in helping 37,000 of those we served with direct financial support totaling \$39.6 million, meeting their pharmaceutical copayment needs when they could not afford to. Our professional case management staff negotiated reimbursement for required treatments valued at over \$26.3 million dollars, through negotiations of pre-authorizations, successful insurance appeals, reconciliation of coding and billing errors, enrollment into available public and private health insurance options, and accessing patient support programs including charity care and manufacturer patient support programs.

Each and every person we were able to work with this year providing both case management and direct financial support through our Co-Pay program are precious to us as they remind us daily of the importance of having sustaining faith in all that is good and right in this world. There is so much for all of us to be thankful for in the midst of the nation's heartache. They are also a reminder that there is much work to be done still as 127,000 people do not represent the entirety of all who need our assistance. It is our challenge for FY 2012/2013 to extend our services to more patients and families, paying forward the faith that the patients we served in the past put in us. It is our belief that our staff's capabilities do bring about significant change in the lives of those who are suffering from illness and its life altering effects. Our work exemplifies who we are and what we believe in so passionately; we are the sustainers of faith, both in our words and more importantly, in our actions. We are grateful to have the opportunity to serve those who need us and know it is only through the strong and committed support of our dedicated professional staff, members of our Boards of Directors who give tirelessly of their time and intellect, the organizations that provide funding for our programs and our patients, who let us into their life, that we are able to achieve measurable results in the lives of so many. I am honored to be one of many leaders at PAF and am proud to call this my professional home.

With Great Appreciation,

Fran Castellow, MSEd President, Operations



Nancy Parksion, Breast Cancer Raymond, CA

I was diagnosed with breast cancer in September 2010. I was treated with surgery, chemotherapy and radiation. The co-payments for the chemo meds were really expensive and I was so fortunate to discover your program.

I want you to know it was a relief for my husband and myself to receive the assistance you gave us. I will be forever grateful.



**Kimberly Alioto, RA** Glenshaw, PA

My name is Kimberly Alioto and I have received assistance from your Foundation this year to help me pay for the medication that I need to be able to function. It is impossible to begin to express the gratitude I feel for the help you have provided to me when I had nowhere else to turn.

I have had Rheumatoid Arthritis since I was fifteen years old. I am nearly fifty-four now. During that large span of time I have had many episodes of exacerbations and remissions. I have

also endured many surgeries to correct or replace the damage to my joints that have resulted from the progression of the disease. Due to these factors I have become a unique individual. I come from a family with many members who have endured many health obstacles. They had to work hard to strive to overcome many obstacles to do the ordinary things that others take for granted. I learned many valuable lessons from them.

The influence of these family members inspired me to become a Registered Nurse. I was able to work for a short period of time after I graduated but I was in a great deal of pain. I had tried many different medication regimes that would help for short periods of time only to fail a year or so later. Consequentially, I was forced to change treatments whenever a new medication was introduced for the treatment of Rheumatoid Arthritis.

This is the only medication that has ever given me consistent control over my disease. If it were not for this medication I would be in terrible pain and unable to walk. I know this because I have had to discontinue taking it prior to any surgeries I have had and suffered some terrible pain until I was able to begin taking it again.

Thanks to the contributors of the Patient Advocate Foundation, I have been able to sustain a semi-normal life for the past year. I am forever grateful for their generosity.

# **11th Annual**



On February 25, 2012, Patient Advocate Foundation held its 11th Annual A Promise of Hope Affair at the

Newport News Marriott at City Center. Our 400 guests came dressed in black and white as they attended "A Black and White Ball...A Night at the Jazz Club."

The VIP Reception was held in the Pearl Ballroom and our guests got their first taste of the Jazz Club as they were entertained



Mistress of Ceremonies, Barbara Ciara, welcomes our guests to the 11th Annual A Promise of Hope Affair.



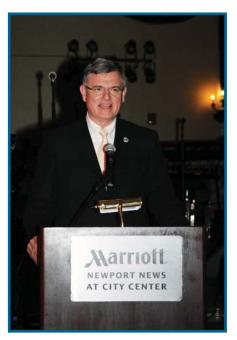
Patient Advocate Foundation Founder and CEO, Nancy Davenport-Ennis makes welcoming remarks to our guests.



PAF Staff checking in our guests

by Ron Lowder, a local saxophonist. VIP guests included US Congressman Robert C. "Bobby"

Scott, Commissioner of the Virginia Department of Health Dr. Karen Remley, Director of the Virginia Department of Health Professions Dr. Dianne Reynolds-Kane, PAF Board Members, Newport News and Hampton City Council Members and representatives from our event sponsors.



PAF Board President, Dr. Dennis Gastineau

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# **11th ANNUAL • A PROMISE OF HOPE AFFAIR**



Members of the Virginia General Assembly, led by Delegate Brenda Pogge (R-96th), present a State Proclamation commemorating PAF's 15 year anniversary.



Dr. McKinley Price, Mayor of Newport News with Nancy Davenport-Ennis, PAF CEO and Congressman Robert C. "Bobby" Scott (D-3rd-VA) after Dr. Price presented a proclamation from the City of Newport News.







Hampton City Council member Christopher Stuart reading a proclamation from the City celebrating PAF's 15th anniversary.



Dr. Karen Remley, Commissioner, Virginia Department of Health addresses our guests.



Director of the Virginia Department of Health Professions, Dr. Dianne Reynolds-Cane speaks to our attendees.

# **11th ANNUAL • A PROMISE OF HOPE AFFAIR**



As our guests attended the Welcome Reception, they were entertained by Becca Fifelski and Tim Tessier who provided acoustical guitar and vocal entertainment. A main feature of the Welcome Reception was our Martini Bar to provide the Jazz Club atmosphere. As guests entered the ballroom, they were greeted by the jazz sounds of the Jim Newsom Quartet, a mainstay of the Hampton Roads outdoor festival circuit.

After dinner, Slapwater took the stage as our guests hit the dance floor. They were followed by the Jim Newsom Quartet who was joined by our special guest performer, Julie Delgado, a California native and Rock & Roll Hall of Fame inductee. Julie was assisted by PAF as she battled breast cancer. She has been performing since 1982, touring with numerous artists. She was inducted into the Rock and Roll Hall of Fame as a member of The Fifth Dimension, having replaced Marilyn McCoo.

In addition to dinner and dancing, our guests had the opportunity to further support PAF by bidding on over 400 silent auction items with a fair market value of over \$33,000.00. Barbara Ciara, managing editor and news reporter from PAF's local CBS affiliate WTKR-Channel 3, served as Mistress of Ceremonies and helped us raise \$9,500.00 for our Scholarship for Survivors Program.



Kathryn West with Amgen is recognized by Jack Ennis for their Event Sponsorship.

Through the support of local and national businesses, PAF Board of Directors and Partners in Progress, the 2012 A Promise of Hope Affair raised over \$323,000.00 through personal contributions, sponsorships, auction bids and in-kind donations. All of the funds raised through this event go directly to support PAF's day-to-day work of helping patients resolve their insurance, job retention and/or debt crisis matters relative to their diagnosis of a chronic, life-threatening or debilitating disease. We invite you to Save the Date of February 23, 2013 for the 12th Annual A Promise of Hope Affair with a theme of "A Night at Casino Royale©...Dinner, Dancing, Games."



Alan Richardson with Event Sponsor Novartis representative Milli Kowalski.

# **11th ANNUAL • A PROMISE OF HOPE AFFAIR**



Dr. Mary T. Christian, founding Board Member and former Virginia Delegate and Nancy Davenport-Ennis

### **ANCHOR COMMITTEE**

Billie Sue Ackerman, Wells Fargo Cindy Black, Old Point National Bank Bruce Breeger, Breeger Media Group Eugene Jordan, Old Point Trust Donna McMahon, TowneBank Jennifer Stuebbe, Dixon Hughes Goodman Eddie Tison, Tison Commercial Property, Inc Nancy Davenport-Ennis, CEO Jack Ennis, Chief Development Officer Alan Richardson, Chief Development Operations Officer Linda Oaster, Development Director-Corporate Relationships Diana Hauser, Development Director-Special Events



Alan Richardson recognizes Kimberly Tiller with Event Sponsor Purdue Pharma.



Alan Richardson recognizes Durinda Biesman with Gold Sponsor inContact





Mike Zincone with Event Sponsor Pfizer and Jack Ennis.



Special guest Julie Delgado entertains the crowd

## **HONORARY CHAIRS**

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Dancing to Julie Delgado and the Jim Newsom Quartet

Senator Barbara A. Favola (D-31st) Senator Mark R. Herring (D-33rd) Senator Linda T. Puller (D-36th) Senator Charles William Carrico, Sr. (R-40th) Delegate Charles D. Poindexter (R-9th) Delegate Joseph R. Yost (R-12th) Delegate Joseph R. Yost (R-12th) Delegate Lacey E. Putney (I-19th) Delegate Ronald A. Villanueva (R-21st) Delegate Barbara J. Comstock (R-34th) Delegate Barbara J. Comstock (R-34th) Delegate Mark L. Keam (D-35th) Delegate Kenneth R. Plum (D-36th) Delegate Kaye Kory (D-38th) Delegate Vivian E. Watts (D-39th) Delegate Timothy D. Hugo (R-40th)

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Submitting bids during our Scholarship for Survivors auction



Our guests bidding on silent auction items



Billie Sue Ackerman with Event Sponsor Wells Fargo and Jack Ennis

> Silver Sponsor Windstream representative Jeff Williams and Alan Richardson

## PATIENT ADVOCATE FOUNDATION GALA TEAM

#### Nancy Davenport-Ennis, CEO

Jack Ennis, Chief Development Officer, Anchor Committee Chair Alan Richardson, Chief Development Operations Officer, Event Chair Diana Hauser, Development Director-Special Events Donna Adkins, Auction Co-Chair Kelly Dye, Auction Co-Chair Tracy Andrus, Application Specialist, Co-Pay Relief (CPR) Program

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Pirate's Cove Adventure Golf Pittsburgh Steelers Pomoco Nissan of Hampton Poquoson Pharmacy Quaker Steak & Lube Red Hot & Blue of Williamsburg Regis Salon, Patrick Henry Mall Ripley's Believe It or Not! **Riverside Wellness & Fitness** Center-Peninsula Ryan Newman Fan Club Sal's Sicilian Pizza Restaurant Sandra Scott Senator Mark Warner Sentara Center for Health & Fitness Showboat Branson Belle Silpada by Terrah Bazemore Simply Selma's Smith's Florist and Gift Shoppe South Beach Grille St. Francis Pet Resort and **Rehabilitation Center** Starbucks #7763, Coliseum Drive Studio Foray Sunday's Blue Box Tanning Resort, Virginia Beach Supercuts, Quarterpath Sushi & Spice Sussex Total Beauty Salon, Angie Wright Sussex Total Beauty Salon, April Johnson and Jessica Winebarger Suter's Handcrafted Furniture Sweet Madeline's Cafe and Catering Tammy Neice Target - Williamsburg, VA Taylor's Do It Center Teresita Ramos, Pampered Chef Consultant The Center for Mind Body Healing The Creative Touch The Gathering Inn at

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Daydream Farm

## **PATIENT DATA ANALYSIS REPORT**

Every April, Patient Advocate Foundation releases the Patient Data Analysis Report (PDAR) which details the patient experience for the calendar year. The PDAR findings were announced during a Hill Briefing in Washington, DC in April. Highlights of 2011 included a restructuring of the PDAR, with chapters being broken out by payer, Medicare, Medicaid, Commercially Insured and Uninsured, with a dedicated chapter for pediatric cases. Patient Advocate Foundation saw a 24.3% increase in the number of patients served in calendar year 2011 versus calendar year 2010, moving to 103,112 patients. For the first time, Texas was the number one PAF referral state, representing 10.1% of the total patient population.

This increase in the number of patients in Texas prompted PAF to expand its **San Antonio office**, moving from 2 case managers to 12 case managers and/or medical intake specialists in a stand-alone office in a medical office park. The staff in San Antonio also works staggered hours so that PAF can continue to offer services from 8:00 a.m. to 8:00 p.m. EST Monday through Thursday and from 8:00 a.m. to 7:00 p.m. on Fridays. Jamilla Williams, PAF Regional

Case Management Director oversees the San Antonio office as well as the other offsite offices, strategically placed in the United States.

# PATIENT DATA ANALYSIS REPORT

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#### Thomas Neilson Beard, Hepatitis C Hickory, NC

The fast, effective, professional service that I got from you was tremendous. This aid came just in time as I was running out of medicine to treat my Hep C. Without your help, I could never have fought this disease, as an interrupted regime of medicine would have meant I would have had to start all over or not have a chance for cure. I wish this country had more programs like yours to help the people that are not as fortunate as some financially. And if there were other programs, they should follow your wonderful model. Thank you again for your quick, timely assistance.

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Patient Congress attendees Vicki Penwell-Alaska, Maryann Colletti-Missouri, Mary Edwards-Maryland and Michelle Flowers-Florida, reporting out from four breakout groups, moderated by Larry Lanier, NPAF EVP of State Government Affairs

#### PAF convened its 13th Annual Patient Congress

in Washington, D.C. on June 20-21, 2012 at The Washington Court Hotel located at 525 New Jersey Avenue, NW. Attendees of the 13th Annual Patient Congress consisted of patients, caregivers, nurses, physicians, pharmaceutical representatives, insurance executives, advocacy group representatives and National Patient Advocate Foundation's Elite Presidential Council Members. This year, we had a total of 96 attendees and of those attendees, 70 people attended hill visits. These attendees came from 39 states and completed 130 Hill visits that included 43 visits with members. Their visits included 66 with Democrats and 62 with Republicans. The key points that attendees brought to Capitol Hill were:



Nancy Davenport-Ennis, PAF Founder and CEO welcomes everyone to the 13th Annual Patient Congress in Washington, DC.

- Prescription Drug User Fee Act (PDUFA) -Drug Shortages and Break Through Therapies
- Safeguarding the Patient Protection Provisions of Patient Protection Affordable Care Act (PPACA)
- Patients' Access to Treatment Act of 2012

Attendees participating in the Capitol Hill Briefing



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Larry Lanier, NPAF Executive Vice President of State Government Affairs



Speaker Vicki Gottlich, Director, Consumer Support Group, Center for Consumer Information and Insurance Oversight (CCIIO) talks about keeping consumers informed during health reform



Monica Volante, Legislative Director, Office of Representative Joseph Pitts (R-PA-16th) discusses the Prescription Drug User Fee Act (PDUFA)

Our attendees started Wednesday morning with breakout sessions addressing four topics that was facilitated by Larry Lanier, NPAF Executive Vice President of State Government Affairs. The four topics were:

- Chronic Disease
- Essential Medications
- Health Insurance Exchanges and Essential Health Benefits
- Medicaid

Nancy Davenport-Ennis, PAF CEO, then moderated speakers on "Presidential Politics-It's Election Year". Tom Kise, Coalitions Director with the Republican National Committee and Mike Ryan, Policy Director with the Democratic Congressional Campaign Committee reviewed their respective party positions. John Schmidt, President and CEO of Schmidt Public Affairs provided tips to the Elite Volunteers for effective media engagement.

After lunch, our attendees heard for Vicki Gottlich, Director, Consumer Support Group with the Center for Consumer Information and Insurance Oversight (CCIIO) who talked about keeping consumers informed during health reform. Next on the agenda was Monica Volante, Legislative Director, Office of Representative Joseph Pitts (R-PA-16th) who spoke about the Prescription Drug User Fee Act (PDUFA), drug shortages and break-through therapies. Margot Sanger-Katz, Health Care Correspondent for the National Journal followed Monica, leading a discussion of safeguarding the patient protection provisions of the Patient Protection and Affordable Care Act (PPACA). Devon Siebert, Legislative Director, Officer of Representative David McKinley (R-WV-1st) led a discussion on the Patients' Access to Treatment Act of 2012. Christopher Kush, CEO of Soapbox Consulting wrapped up the Capitol Hill Briefing and Workshop with distribution of the Hill Visits schedules and tips for the Hill.



Attendees at the Welcome Reception and Educational Expo

After the Capitol Hill Briefing, our attendees participated in a Welcome Reception and Educational Expo. They were able to mingle amongst themselves as well as visit with other non-profit patient groups. Those groups included:

- American Society for Radiation Oncology (ASTRO)
- Breakaway from Cancer
- Cancer Support Community
- Colon Cancer Alliance
- Co-Pay Relief
- Fight Colorectal Cancer
- FORCE: Facing Our Risk of Cancer Empowered
- Imerman Angels
- International Myeloma Foundation
- Kidney Cancer Association
- LIVESTRONG
- Lung Cancer Alliance
- National Coalition for Cancer Survivorship
- Patient Advocate Foundation
- Prevent Cancer Foundation
- Women Magazine
- Young Survival Coalition
- ZERO-The Project to End Prostate Cancer







Thursday, June 21, began with a breakfast at the Washington Court Hotel, giving our attendees one last strategy session prior to visiting Capitol Hill and their elected officials. Lunch was held in the Rayburn House Office Building and our attendees wrapped up their visits in the afternoon. That evening, there was a Dinner Reception, where attendees could discuss their day on the hill followed by a Dinner Symposium. We were honored to have Michael Samuelson. President of Samuelson Health & Wellness address our attendees and tell about his personal journey as a male breast cancer survivor. We were also honored to have Representative David McKinley (R-WV-1st) share the podium and talk about the Patients' Access to Treatment Act of 2012, (H.R. 2049) of which he is the sponsor. The Act would "limit co-payment, coinsurance and other cost-sharing requirements applicable to prescription drugs in a specialty drug tier to the dollar amount (or its equivalent) of such requirements applicable to prescription drugs in a non-preferred brand drug tier, and for other purposes."

Our attendees were asked to summarize their Patient Congress experience. Below is a sampling of those summaries:

"I was extremely impressed with the event coordination and organization which was seemingly flawless. The PAF is clearly a top-notch organization with exemplary leadership."

"Well organized and professional conference with terrific speakers."

"Great experience! It's gratifying to feel like you can make a difference."

"It was an excellent example of patient advocacy at its best!!"



A discussion of safeguarding the patient protection provisions of the Patient Protection and Affordable Care Act (PPACA) is led by speaker Margot Sanger-Katz, a health care correspondent with the National Journal



Tom Kise, Coalitions Director with the Republican National Committee and Mike Ryan, Policy Director with the Democratic Congressional Campaign Committee are thanked by Nancy Davenport-Ennis after speaking to the Patient Congress attendees on the upcoming election.



Jake Silberg, a Scholarship for Survivors recipient addresses our Patient Congress attendees

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#### **EDUCATE • EMPOWER • ENACT**

Patient Advocate Foundation would like to thank the following companies for their financial support of the 13th Annual Patient Congress:

- AmerisourceBergen
- Amgen Oncology
- Boehringer-Ingelheim
- Bristol-Myers Squibb
- Celgene
- Eli Lilly and Company
- Endo Pharmaceuticals
- Genentech
- GlaxoSmithKline
- Jazz Pharmaceuticals
- Millennium: The Takeda Oncology Company
- Pfizer Oncology
- Teva Pharmaceuticals



Attendee Renee Blechner form Wisconsin participating in the Capitol Hill Briefing



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Attendee Janice Ford Griffin from Texas asking a question to one of our panelists





Gwen Mayes, NPAF Executive Vice President of Government Affairs

Devon Seibert, Legislative Director, Officer of Representative David McKinley (R-WV-1st) discusses the Patients' Access to Treatment Act of 2012



Attendee Vicki Penwell from Arkansas on a Hill Visit



Trevor Simon, NPAF Health Policy Analyst, Dr. Dennis Gastineau, PAF Board President, Senator Rand Paul (R-KY), Gwen Mayes, NPAF Executive Vice President of Government Affairs, and Nicholas Harper, NPAF Elite Volunteer from Kentucky



Brad Tallamy, NPAF Manager Government Affairs, Elite Volunteer William Thomas and US Senator Mike Crapo (R-ID)



Dinner Symposium speaker, author Michael Samuelson, President, Samuelson Health & Wellness



Representative David McKinley (R-WV-1st) speaks to the Patient Congress attendees during Dinner

Representative McKinley with PAF Chief Development Officer Jack Ennis and PAF/NPAF CEO Nancy Davenport-Ennis





Patient Congress Honorary Chairpersons



#### **United States Senate**

Senator Daniel K. Inouye (D-HI) Senator Jeanne Shaheen (D-NH) Senator Ben Cardin (D-MD) Senator Thad Cochran (R-MS) Senator Ben Nelson (D-ME) Senator Robert P. Casey, Jr. (D-PA) Senator Tim Johnson (D-SD)



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Congressman Mike Thompson (D-CA-1st) Congresswoman Lucille Roybal-Allard (D-CA-34th) Congresswoman Loretta Sanchez (D-CA-47th) Congresswoman Rosa DeLauro (D-CT-3rd) Congresswoman Diana DeGette (D-CO-1st) Congresswoman Eleanor Holmes Norton (D-DC-At) Congressman Hank Johnson (D-GA-4th) Congressman Jesse L. Jackson, Jr. (D-IL-2nd) Congressman Cedric Richmond (D-LA-2nd) Congressman Chris Van Hollen (D-MD-8th) Congresswoman Nita M. Lowey (D-NY-18th) Congressman Maurice D. Hinchey (D-NY-22nd) Congressman Dennis Kucinich (D-OH-10th) Congressman Steven C. LaTourette (R-OH-14th) Congressman Chaka Fattah (D-PA-2nd) Congressman Jason Altmire (D-PA-4th) Congressman Allyson Y. Schwartz (D-PA-13th) Congressman David Cicilline (D-RI-1st) Congressman Jim Langevin (D-RI-2nd) Congressman James Clyburn (D-SC-6th) Congresswoman Kay Granger (R-TX-12th) Congressman Charles Gonzalez (D-TX-20th)

## **Scholarship for Survivors Academic Award Program**

The PAF Scholarship for Survivors Academic

Award Program was created in 2000 by Founder and PAF CEO Nancy Davenport-Ennis in honor and memory of the thousands of young adults who have had their lives forever changed as a result of a diagnosis of cancer or another life-threatening disease. Educational scholarships are offered to those who have suffered or are suffering a life threatening disease or chronic condition. These students have excelled academically, volunteer in the community and desire to pursue a secondary education.

#### THE CHERYL GRIMMEL AWARD

Insup Lee Falls Church, VA School: Harvard College

#### THE MONICA BAILES AWARD

Brittany Stene Plano, TX School: Collin College

#### THE MARK STEPHENS AWARD

Miles Austrevich Chicago, IL School: Yale University

#### THE KAREN L. REEDER AWARD

Jacob Silberg Maplewood, NJ School: Harvard College

#### THE ROBIN PRACHEL AWARD

Marquis Martin North Augusta, SC School: University of Alabama in Huntsville

## THE U.S. REPRESENTATIVE JO ANN DAVIS AWARD

Nathan Hertz Wichita, KS School: University of Texas at San Antonio To date, PAF has awarded 47 scholarships totaling over \$350,000. Each Scholarship recipient receives a \$3,000 award annually for each year that he/she is enrolled full time in a higher education program. They must maintain a GPA of 3.0 or higher and complete community service hours each semester. Award recipients are notified in June of each year and the recipients for the 2012/2013 academic year were:

## THE UNITED HEALTHCARE FOUNDATION AWARD

Hanna Hughes Rochester, MN School: University of Minnesota Duluth

## THE UNITED HEALTHCARE FOUNDATION AWARD

Kahina Louis Miramar, FL School: University of Florida

## THE UNITED HEALTHCARE FOUNDATION AWARD

Kimberly Santo Plantation, FL School: University of Florida

## THE UNITED HEALTHCARE FOUNDATION AWARD

Joshua Weinstein Irvine, CA School: University of California Berkeley

#### SCHOLARSHIP FOR SURVIVOR RECIPIENTS

Hunter Durfee Troy, NH School: Keene State College

Amanda Archibong Sugarland, TX School: University of Texas at Austin



## In Conclusion

As we started this FY 2011/2012 Annual Report, we posed the question of how do you measure a year. For 127,808 patients, which represents a 44% increase over FY 2010/1011, we can measure a year by their stories of how PAF was able to help them solve their insurance and healthcare access problems. It can be measured by the 1,418,219 case contacts that were made to the various stakeholders to resolve the patients' cases and the \$26.3 million we obtained in debt relief for those patients. PAF can measure the year by the 76 data reports that were provided to members of the US Congress as well as the data provided to US Department of Health and Human Services. The Co-Pay Relief program opened two new disease silos in FY 2011/2012 in addition to the changes made to how patients were assisted. Five hundred twenty-five thousand six hundred minutes....

#### GENERAL DONORS

#### July 1, 2011-June 30, 2012

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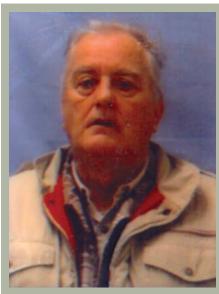
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#### Edward J. Grant, Prostate Cancer Canton, OH

When I was diagnosed with Prostate Cancer, which had spread into lymph nodes, I could barely function. I was in a daze. The first thought is, am I going to die? The second thought is, how am I going to pay? Then I started treatments at Tri-County Cancer Center. There I met the person who administers the Co-Pay Relief program. After speaking with her and receiving the caring correspondence from Co-Pay Relief offices, there is some light and hope coming through the darkness.

Most of my family has died. I am living alone. The mass of paperwork is hard to handle but, the Co-Pay Relief Program give that extra help that makes a great difference. It's hard to believe that complete strangers care about someone they have never met.

Andy Ramlatchan Jeanette Ramos Kenneth and Janet Raymond Ruth Anne Reed Mary Reynolds Marvin Rhoades Avis Richardson Rob Rifkin, M.D., P.C. Rita Robinson **Rocquel Robinson** Maria Rodriguez Stephanie Rodriguez Nanette Roos Dana Roscopf Erica Rosenthal Rotary Club of Newport News Foundation Tina Rudolph-Smith Maria Sanchez Jon Sands Shequeta Sanford Tina Santiago Jennifer Saulman Rosa Linda Schuchardt Paul Schutt Sandra Scott Karen Seitz Muhammed Shakeel **Michelle Shanks** Lisa Shaw Mark Sherwood Lisa Shird Jane Siano Antoinia Smith Lewis Smith **Michelle Smith Deb Smith-Porter Michelle Spriggs** Paul Sowash Spectrum Foundation Jennifer Spivey C. Janelle Stenger **Russell Stewart** 

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- In Memory of Margaret Ostrowski Donna Diaz Anne Durkin Patricia Gettlings Mary Helming Elizabeth McGann

Jane Northrup Melendrez for patient, Gabriel Melendrez, Hepatitis C Globe, AZ

Because of this foundation, my husband will have a chance to finish the medicine and have a chance for life.



**Dawn Jester, Breast Cancer** San Marcos, TX

I sincerely appreciate the opportunity to apply for and receive co-pay relief from your program.

With your program's generous approval, some of my deductible for this year and the copayments for chemo treatment will hopefully be paid to my chemo doctor. I also turned in about \$500 worth of prescription co-pays from a period of 09/02/11 to this month (6 ½ months). If not for your assistance, I would be in financial trouble. This is such a worthwhile

program and I am grateful that it exists. Thank you for the work you do to help cancer survivors with their treatments.

**Combined Federal Campaign** PAF is a participant in the

**Combined Federal Campaign** (CFC) which was established by the United States government as a way to provide Federal civilian, postal and military personnel the opportunity to support eligible non-profit organizations providing health and human service programs. The mission of the CFC is "to promote and support philanthropy through a program that is employee focused, cost-efficient, and effective in providing all federal employees the opportunity to improve the quality of life for all." PAF's CFC number is 10681. You are also able to designate Patient Advocate Foundation with your local 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. PAF's FEIN number is 54-1806317.



Marcia D. Braun, Osteoporosis Miami Springs, FL

I learned about your foundation from the Accredo Pharmacy when I started looking into the possibility of obtaining the specialty drug, Forteo that my doctor had recommended for me. With my co-pay cost too high to consider on my school teacher retirement income, I was so happy to learn that your foundation actually wanted/existed to help people like me.

Even before I realized that you were located close to my daughter in Newport News, I felt a personal concern from so many of you. Robert started me out and then there

was Sharon, Shakweena and Debbie and other, all helping me along the way. I faxed my enrollment application on May 16th, and was both thrilled and relieved to receive your letter of award the first part of June.

I truly appreciated the direct billing between you and Accredo, which saved me being "in the middle" regarding payment. It was all so very efficient – even to the point of receiving a statement from Medco showing that the co-pay had been paid – and quickly too.

I know that you help hundreds of people in these ways, so my appreciation goes beyond my personal experience. Thank you, Patient Advocate Foundation, not only for helping, but for helping in such a caring and professional way. Would that others would emulate your ways!

## **PAF FINANCIAL STATEMENTS**

## Patient Advocate Foundation Statements of Financial Position

Years Ended June 30,	2012	2011
Assets		
Current assets		
General operating cash and cash equivalents	\$ 1,415,140	\$ 3,187,235
Restricted CPR cash and cash equivalents	26,031,769	38,331,347
Unconditional promises to give	149,943	102,925
Interest receivable	48,790	56,501
Related party receivable	4,078	2,131
Service contract receivable	446,074	501,299
Employee travel advances	920	21,728
Inventories	94,500	86,957
Prepaid expenses	171,200	235,869
Investments and cash equivalents	1,920,717	1,943,750
Total current assets	30,283,131	44,469,742
Property and equipment - net	1,400,184	1,542,011
Other assets		
Refundable deposits	103,631	108,540
	\$ 31,786,946	\$ 46,120,293
Liabilities and Net Assets		
Current liabilities		
Current portion of obligation under capital lease	\$ 54,951	\$ 68,477
Accounts payable and accrued expenses	453,431	631,953
Deferred revenue	1,261,366	2,322,968
Accrued vacation leave	357,156	406,593
Total current liabilities	2,126,904	3,429,991
ong-term liabilities		
Obligation under capital lease - less current portion		54,950
Total liabilities	2,126,904	3,484,941
Unrestricted	1,707,558	2,360,255
Temporarily restricted	26,031,769	38,331,347
Permanently restricted	1,920,715	1,943,750
Total net assets	29,660,042	42,635,352

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

Patient Advocate Foundation

Statements of Activities

Years Ended June 30,		2012	2			2011	-	
	Unrestricted	Temporarily   Restricted	Permanently Restricted	Total	Unrestricted	Temporarily F Restricted	Permanently Restricted	Total
Revenues, gains and other support Contributions								
Grants	\$ 4,610,445	\$27,124,500	۰ ک	\$31,734,945	\$ 6,849,584 \$	\$27,183,586	۔ ج	\$34,033,170
Private and public donations	- 96,676		I	96,676	82,268		ı	82,268
Donated services and materials	105,943	ı	I	105,943	166,699	I	I	166,699
Program Administration	10,389,380	'	I	10,389,380	8,884,423	ı	I	8,884,423
Patient Congress	285,689	ı	ı	285,689	225,920	ı	ı	225,920
Prescription Access Point	I	ı	I	'	750,000	ı	I	750,000
Promise of Hope	290,048	'	I	290,048	285,606	ı	I	285,606
Miscellaneous income	338,084	ı	I	338,084	453,652	ı	I	453,652
Investment income (loss)	295,330	I	(23,035)	272,295	285,788	I	(30,627)	255,161
Net assets released from restrictions Satisfaction of program restrictions								
Financial Aid Awards	39,424,078	39,424,078 (39,424,078)	'	I	19,087,061 (19,087,061)	(19,087,061)	'	I
Total revenues, gains and								
other support	55,835,673	55,835,673 (12,299,578)	(23,035)	43,513,060	37,071,001	8,096,525	(30,627)	45,136,899
Expenses								
Program services:								
Patient services	6,719,227	I	1	6,719,227	8,832,046	I	I	8,832,046
Co-Pay Relief	43,800,408	I	I	43,800,408	21,711,008	I	I	21,711,008
Service contracts	2,900,039	I	I	2,900,039	2,354,439	I	I	2,354,439
Supporting services: Management and general	1,922,231	I	ı	1,922,231	1,873,430	I	ı	1,873,430
Fundraising	1,146,465	I		1,146,465	1,215,215	I	ı	1,215,215
Total expenses	56,488,370	'	ſ	56,488,370	35,986,138		'	35,986,138
Change in net assets	(652,697)	(652,697) (12,299,578)	(23,035)	(23,035) (12,975,310)	1,084,863	8,096,525	(30,627)	9,150,761
Net assets - beginning of year	2,360,255	38,331,347	1,943,750	42,635,352	1,275,392	30,234,822	1,974,377	33,484,591
Net assets - end of year	\$1,707,558	\$26,031,769	\$1,920,715	\$1,920,715 \$29,660,042	\$2,360,255	\$38,331,347	\$1,943,750 \$42,635,352	\$42,635,352

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

## FY 2011/2012

#### Combined Functional Expenses FY11/12

Program Services	\$53,419,674.00	94.6%
Management & General	\$1,922,231.00	3.4%
Fundraising	\$1,146,465.00	2.0%
Total	\$56,488,370.00	

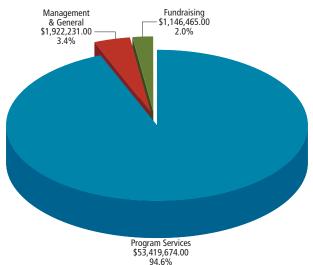
#### Combined Revenue and Earnings FY11/12

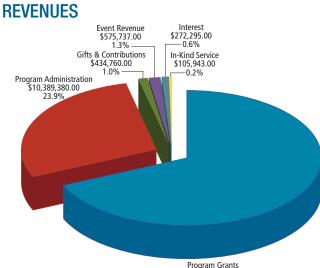
\$31,734,945.00	72.9%
\$10,389,380.00	23.9%
\$434,760.00	1.0%%
\$575,737.00	1.3%%
\$272,295.00	0.6%
\$105,943.00	0.2%
\$43,513,060.00	
	\$10,389,380.00 \$434,760.00 \$575,737.00 \$272,295.00 \$105,943.00

#### Combined Program Activities FY11/12

Case Management, Outreach & Education Programs	\$6,320,242.00	11.8%
Financial Aid Grants	ψ0,020,242.00	11.070
& Administration	\$43,579,633.00	81.6%
Advocacy and Government		
Relations	\$619,760.00	1.2%
Service Contracts	\$2,900,039.00	5.4%
Total	\$53,419,674.00	

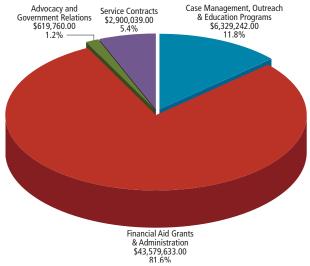
#### **FUNCTIONAL EXPENSES**





Program Grants \$31,734,945.00 72.9%

#### **COMBINED PROGRAM ACTIVITIES**







Sally Scharff, Osteoporosis San Antonio, TX

I would like to thank you for your help in reimbursing me for my co-payments. I was diagnosed with osteoporosis at the age of 47 (secondary to taking steroids for multiple sclerosis) and I had 3 fractures in my foot just from walking. It is difficult enough to live with the pain and problems from a chronic illness, but the financial aspect is just as bad. I am so grateful to your organization for helping me with my medical expenses!

## PAF STAFF • FY 2011/2012

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## 63

## **Employee Relations Committee**

The Employee Relations Committee's (ERC) mission is to serve our workforce by improving upon and sustaining a positive working environment. The ERC promotes positive morale with all levels of staff through effective communication, recognition, education, philanthropic, and team building events. The committee is comprised of staff representing all departments in the organization and rotates annually to increase participation. Some of our annual traditions are Spirit Week, annual PAF t-shirt contest, and the food bank drive.

## **ACKNOWLEDGEMENTS**

EDITOR IN CHIEF	Nancy Davenport-Ennis, Chairman of the Board, Founder and Chief Executive Officer
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	www.copays.org www.colorectalcareline.org
	www.Narcolepsy.PAFCareline.org
	Email: info@patientadvocate.org
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