



PATIENT SERVICES INCORPORATED

“MAKING THE GIFT OF HEALTH A LIFETIME BENEFIT”[®]

Reflecting Upon 2015

By Dana Kuhn, Ph.D., PSI President

The festive holiday season will soon be behind us and the New Year will begin leaving “Old (auld) Acquaintances” behind as memories. However, 2015 had some good memories for PSI which are worth mentioning.

First, we completed our IT rebuild of our database. It was becoming outdated, and we really needed to rebuild in order to handle additional (and larger) programs while implementing cost-saving efficiencies. As the cost of health insurance and the cost of prescription drugs continue to rise, we needed to find ways to create efficiencies so donated dollars could be stretched further to help patients in need. Our new “robust” database allows donors, referral entities, and mostly patients to access services through on-line portals. These portals allow patients to quickly apply for assistance as well as view their personal PSI files in real time. PSI can now accommodate larger programs providing “speed to therapy” and “speed to payment.” This makes all stakeholders happy.

Second, PSI advocated to maintain and protect current assistance programs that were scrutinized across all non-profit platforms, due to compliance concerns made on behalf of the U.S. Office of the Inspector General (OIG). This concern addressed all non-profit foundations and was released in the form of a “Special Advisory Bulletin.” When it seemed OIG did not understand the rationale behind the non-profit patient assistance model pioneered by PSI, the continuation of some of our current programs was endangered. PSI went to our friends on Capitol Hill for assistance. We



presented our case to legislators, and they respectfully wrote letters to the OIG expressing their concerns. OIG listened and provided ways for PSI to continue to provide compliance within all of our programs. Our advocacy also allowed other non-profit foundations to continue their patient assistance programs.

Third, PSI, along with the American Kidney Fund, advocated for patients whose marketplace insurance plans refused premium payment from charitable organizations. This barrier created hardship for the most vulnerable populations and literally took policies from their reach. Charitable organizations, a stop-gap creation in the United States saving the government millions and billions of dollars, were now being threatened. Once again, PSI went to our friends in Congress. Legislators were perplexed, and after writing a few letters with no satisfactory results from the Administration, H.R. 3742 was introduced on October 9, 2015. This bill will add charitable organizations to the identified federal programs from which marketplace insurance plans would have to accept premiums on behalf of patients. PSI again led the charge in advocating for patients who had no voice or power with this unjust barrier.

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Patient Services helps chronically ill patients make ends meet

By PatientDaily.com | Thursday, Nov 5, 2015

Patients suffering from chronic illness are often forced to choose between basic necessities and their own health care, something a non-profit patient assistance program is working to change.

Even though they have health insurance, nearly 10 million adults will face bills they're unable to pay, according to a study by the price comparison company NerdWallet. Nearly 10 million others will be unable to pay for rent, food and heat because of their medical bills.

That's where Patient Services, Inc. comes in for patients suffering from rare or chronic diseases. PSI is a national non-profit, designed to be a short-term solution for patients who, despite being insured, can't make ends meet.

"We make it so they don't have to make that decision," Mandy Herbert, director of marketing and public relations at PSI, recently told *Patient Daily*. "They can get the treatment they need and focus on what's important – living their lives."

PSI provides premium and copay assistance to those patients with rare or chronic diseases, Herbert said. To benefit from PSI, a patient must be insured and meet other eligibility requirements that vary by program. Once a patient is accepted into PSI's program, they can focus on healing while PSI picks up the tab through various donations.

Donations come from a large pot of donors, Herbert told *Patient Daily*, including pharmaceutical companies, patient chapter support groups and individuals. PSI makes payments directly to the patient's insurance company.

"There is an ever-increasing need for financial assistance with premiums and copayments," Herbert said. "Even with financial subsidies provided through the Affordable Care Act and marketplace policies, patients with expensive rare disorders still don't have the capital to meet the premium out-of-pocket costs that are being asked of them."

Founded in 1989, PSI was the first nonprofit patient assistance program of its kind.

PSI President Dana Kuhn suffers from a chronic illness himself, according to his company biography, and knows first-hand the expense it can create. Before founding PSI, Kuhn was a clinical counselor, working with families who had children with cancer. Herbert told *Patient Daily*, it was during that time he



Nearly 10 million people will be unable to pay for rent, food and heat because of their medical bills.

realized the financial challenges families faced were just as difficult as the emotional ones.

"He thought it would be great if there were some sort of support system for these families so they wouldn't have to worry about the financial aspects of a chronic illness," Herbert said. "So they could only deal with the emotional challenges and give support there, and then those financial challenges would be taken care of for them – they're focusing on family and getting well."

PSI continues to take donations from new organizations to help families finance medical care. They are also always accepting applications from new patients, though patients must have health insurance to apply.

The open enrollment period for the country's health insurance marketplace is already in full swing. The enrollment period lasts from November through January 31.

Source: PatientDaily.com | <http://patientdaily.com/stories/510646621-patient-services-helps-chronically-ill-patients-make-ends-meet>

Reflecting Upon 2015

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All in all, PSI has proven to all that we are not only a premier charitable patient assistance program but also a powerful leader in advocating for patients who are voiceless. So as we bring in the New Year, let's not forget these "old acquaintances," but continue to preserve our rights and needs as patients. Let's not be meek, but be bold in advocating for our health and the health of others. May the blessings of the season and new year lead you into 2016!

With much appreciation,

Dana A. Kuhn, Ph.D.

President and Founder
Patient Services, Inc.



PSI Hosts Congressional Briefing to Support the *Access to Marketplace Insurance Act*

By James M. Romano, Director of Government Relations

On Thursday, November 19, 2015, Patient Services Incorporated (PSI), along with its advocacy partner, the American Kidney Fund (AKF), hosted a Congressional briefing entitled – *Strengthening the Safety Net through Health Insurance Premium Assistance*. This briefing brought together patient advocates and Congressional staff to draw attention to an issue affecting patient



Congressman Kevin Cramer urges legislative support for H.R. 3742.

assistance organizations and urge support for H.R. 3742, *Access to Marketplace Insurance Act*. This legislation was introduced in October by Congressman Kevin Cramer (R-ND).

PSI and AKF have spent the last two years advocating for the importance of health insurance premium assistance, even with the advent of the Exchange/Marketplace plans created under the Affordable Care Act. The

other aspects of the issue by speaking of discrimination, “This trend among insurers to deny charitable assistance to the sickest patients is de facto discrimination against Americans with disabilities.” PSI President, Dr. Dana Kuhn, emphasized the humanitarian aspect of this issue, “Today PSI lessens the financial burden on American families battling rare and chronic illnesses and ensures access to the treatments and therapies they need.”

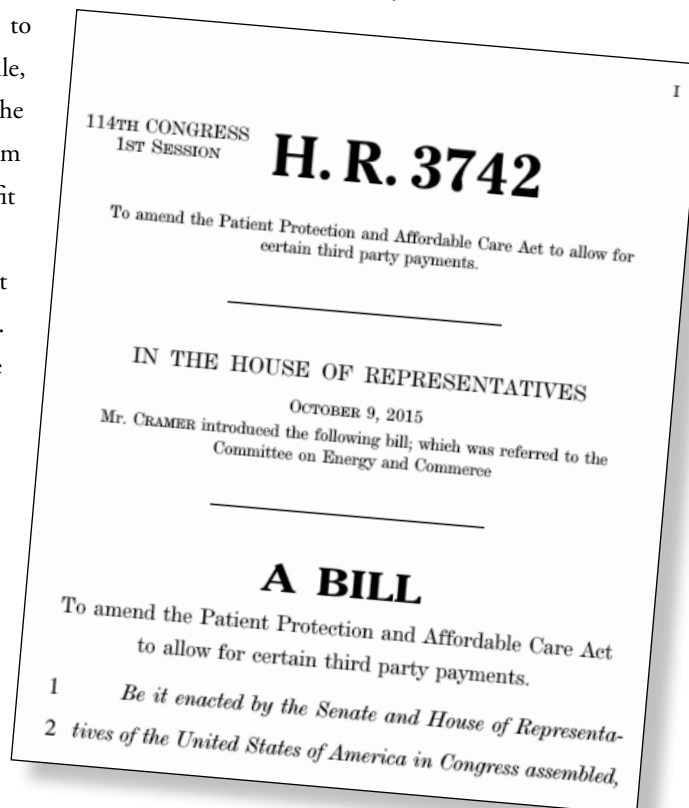
Two patient advocates spoke regarding their personal experiences, Mr. Eric Dolby and Mr. Jordan Martin. Each described their lives battling expensive and rare conditions. Each presented an alternate reality of their lives without the treatments they need if neither



PSI President Dana Kuhn addresses Congressional staffs to the importance of H.R. 3742.

legislation and the bill are the reaction to a March 2014 CMS Interim Final Rule, which allows health insurance carriers in the exchanges to prohibit third-party premium assistance by entities including nonprofit charities like PSI.

The briefing featured several important speakers including patient advocates. Congressman Kevin Cramer (R-ND), the champion of the legislation, emphasized the importance of charitable organizations by stating, “Individual Americans should also have the right to organize and do the same through their charity of choice. We need to allow charities to be charitable.” The president and CEO of the American Kidney Fund emphasized



individual had health insurance premium assistance from charitable organizations like PSI or AKF. Following the briefing, the advocates fanned out across Capitol Hill to meet with Congressional offices. The group had the opportunity to meet with Congressman James Clyburn (D-SC), the assistance Democratic leader to discuss this problem. PSI was excited and proud to organize the briefing. If you have any questions on this legislation or would like to become involved, please contact me directly at jromano@unecpsi.org.



Patient Services, Inc. Hosts *Hope & Health Gala*

By Mandy Herbert, MBA, Director of Marketing and Public Relations

PSI held their annual gala, themed Hope & Health, on October 21, 2015, in historical Boston. Against the breathtaking 180-degree views of downtown Boston via



PSI founder Dana Kuhn with Robert Coughlin, CEO of Massachusetts Biotechnology.

two-story panoramic glass walls, the evening celebrated PSI's patient assistance model and how it has restored hope and health to hundreds of thousands of patients since its inception in 1989.

In welcoming the 100-plus invited guests, PSI founder Dana Kuhn, Ph.D., said, "Through our combined efforts over the past 26 years, we have built a bridge and provided a safety net

to hope and health. Those in the audience tonight, pharmaceutical companies, specialty pharmacies, patient chapters and representatives, have all aided in PSI's success and shared our passion for restoring hope to those in need."

The evening, emceed by Jason Roop of "Style Weekly," began with a cocktail reception at the State Room Mezzanine overlooking Boston's harbor and city lights, a performance by the Boston Jazz Trio, and a seated dinner in the great room of the building. The evening's



Auctioneer John Terrio works his magic at the live auction.

program included a "wicked" greeting from Boston native, Robert Coughlin, CEO and president of Massachusetts Biotechnology Council, an address from PSI founder Dana Kuhn, and an awards ceremony honoring five different individuals and corporations. Auction Knights auctioneer John Terrio hosted a live auction featuring luxury trips to Charleston, S.C., Lake Tahoe, Napa

Valley, and a Royal Caribbean cruise. Other items that were crowd pleasers included VIP access to the annual Rockefeller Center tree lighting as well as the ultimate Boston Red Sox VIP experience.

In addition to the awards, music, and entertainment, PSI was honored to have two patients in attendance, Charlotte Mattison and Lamont Banks. Each gave a touching testimony and shared how PSI has restored hope and



Charlotte Mattison and Lamont Banks gave touching speeches of hope and health.

health to their lives. Lamont Banks, PSI Bleeding Disorders patient, said, "PSI has given me the hope and drive to be more than my illness, to not let my health prevent me from doing what I love." Charlotte, PSI Alpha-1 Antitrypsin Deficiency patient, said, "Without PSI, I would not be standing in front of you today, defying the odds of survival. PSI has given me hope and health and allowed me to live a life of happiness, experiencing all life has to offer – my children growing up and getting married, the birth of my grandchildren, weddings for my grandchildren, and even the birth of great-grandchildren."

Special guest Robert Coughlin, CEO and president of Massachusetts Biotechnology Council, added, "The services that PSI provides to patients nationwide is commendable. I'm proud to stand by their side."

Gary Cross, PSI chairman of the board, concluded to the audience, "After 15 years as a member of PSI's Board of Directors, I am still amazed by the staff's gift for putting a smile of hope on the face of a patient. To all of our friends and visitors this evening, thank you for your support, thank you for giving so many hope."



Mandy Herbert with award winners Sasha Zatyryka and Jonathan James.



PSI Chairman of the Board Gary Cross with daughter Jennifer and wife Karen.



The Hope & Health Gala celebrated PSI's patient assistance model of helping those in need.

FIVE AWARDS HIGHLIGHT THE HOPE & HEALTH GALA EVENING



Pete O'Malley, VP, US Patient Advocacy for Baxalta Inc., celebrates the Patient Champion Award with members of the Baxalta team.

Patient Champion Award

PSI confers this award upon a community leader whose selflessness and dedication to patients best represents the values and importance of personal care. PSI presented the award to Pete O'Malley, Vice President, US Patient Advocacy for Baxalta Incorporated. Pete is a true patient advocate with a passion for caring for patients. Through advocacy, he provides patients with the hope of accessing what they need. If he cannot provide it directly, he helps them resource it or creates a program to meet their needs. Pete becomes the friend of every patient he meets.



Mark and Sasha Zatyрка

Bradley Cross Lifetime Achievement Award

PSI inaugurated this award for an individual's specific, positive, extraordinary and enduring accomplishments. The 2015 recipients were Mark and Sasha Zatyрка. Passing on hope is a constant in their lives. PSI Chairman of the Board Gary Cross, his wife Karen Cross, and daughter Jennifer Cross presented the award. This was an emotional moment as the award is named after their son, the late Bradley Cross. The Cross family lost their hemophiliac son after he became infected with HIV through contaminated blood used for his treatment.

Chairman's Award

This award is given to a community leader who honors and best embodies the purpose and goals of ensuring that chronically ill patients receive affordable access to care. This community leader is recognized for excellence in service, dedication, and ongoing efforts to serve patients in need. PSI presented the award to Jonathan James, executive director of Hope for Hemophilia. His organization, Hope for Hemophilia, has helped thousands of families through difficult seasons of crisis caused by hemophilia. Most of all, Jonathan has a heart for helping people regain hope and health.



Jonathan James
Executive Director,
Hope for Hemophilia



Michael Mackaravitz
Bayer HealthCare

Eugene F. Kuhn Memorial Award

Named for PSI's first treasurer, PSI bestows this award on a community leader to recognize their ongoing generosity, support and friendship. PSI conferred this year's award to Bayer HealthCare Pharmaceuticals, Inc. for supporting PSI in restoring hope and health to the lives of patients living with an expensive chronic illness or condition. The company's aim is to discover and manufacture products that will improve human health worldwide by diagnosing, preventing, and treating diseases.

Extraordinary Support Award

This award recognizes a person who has made outstanding contributions of service to ensure that patients living with a chronic illness maintain quality of life and exceptional treatment. PSI presented the 2015 Award to Val Bias, CEO of the National Hemophilia Foundation (NHF). While Val could not attend the event, he sent his thanks via video and congratulated PSI on its commitment to restore hope and health to those in need. Val has been and continues to be an advocate for the most vulnerable populations achieving the hope and health they long for every day.



Jim Romano with longtime PSI friend Stephanie Fierman.



PSI's Board of Directors gather together at the Hope & Health Gala.



Kelly Fitzgerald and Mandy Herbert share a light moment at the Gala.



A Year in Testimonies



PSI has been providing my co-pay amount for a chemo drug that keeps me in remission from CML. Without this help, I wouldn't be here today. Supporting this cause is the least I can do to show my appreciation for your organization. God bless you all.

PSI CML Patient

Dear PSI,

I am the caretaker of a recipient of your wonderful program. I know you want letters from people who have been the patient, but I want to express my gratitude as the caretaker of the recipient. Please understand.

We, my husband and I had a double lung transplant. I say "we" because it's affected my quality of life as well as my spouse. The transplant went well; however, in the process of taking the medication to sustain life, he developed Leukemia and was told if he didn't take the medication for that he would not survive. I thank God there is a pill he can take instead of going thru the alternative. In addition to the costly meds from the lung transplant, we now had the monumental co-pay of the Leukemia meds. If it had not been for the generosity of PSI to assist us, I really don't know what we would have done. I encourage everyone I encounter to please give to this wonderful organization that helps so many people. It's really life changing.

PSI Leukemia Patient

Thank you and congratulations to all who make PSI possible! I know that I could not maintain a less pressured life with my CML if it were not for Dr. Dana's ideas and staff support! His own story is amazing and a tribute to his spirit and motivation for others. He deserved his award. If I can do anything, please let me know as you reach out to legislators, which I did this past month.

PSI CML Patient

Hello PSI.

Thank you for your fantastic update in the fall newsletter. I was so moved by everything that I read and knowing the history of how the visions of PSI came about... amazing. You have been such a blessing to me and my family for the last few years. Your service and heart are so evident in your mission. It was just over 10 years ago I was diagnosed with CML. You are once again amazing in the impact you made on my life and our family. Thank you.

PSI CML Patient

Thank you for your fall greetings. I particularly thank you for all the medical and financial help you have given me. If it wasn't for your program, I would be without the medication I need to survive. You have certainly been like a gift sent from heaven and I thank you so very dearly. A special thanks to all responsible for donating and organizing a program such as PSI. You guys are truly wonderful!

PSI Patient

Dear PSI ACCESS:

Without the guidance from this office, I'm sure my case for SSDI would have dragged out for years. Your collective knowledge on rare diseases and how to work within the laws of SSDI enabled me to win at the initial level. This has relieved me and my family of an additional burden. Thank you. This organization has made the difference in my life! From first words of advice, documentation, and questions to the final acceptance, you have made a huge difference!

PSI PEMA patient

Dear PSI:

I have received a check for the payment of my ALS medication. My husband and I send a heartfelt thanks to you for your assistance in paying for this medication. Dealing with this disease is helped by the kind assistance of your organization.

Also, I would like to say that I returned to Houston for my 3-month checkup at the MDA/ALS clinic. Thankfully, I received a good report on a lot of the tests. It always adds a feeling of hope and optimism to get positive results. A lot of good comes from taking all the helpful medications. We appreciate your continued support. Thank you.

PBA Patient

Dear PSI:

Thank you so much for all you are doing for me and my wife. Diagnosed with cancer in 2010, I underwent a total of three major surgeries before Duke pronounced me cancer free in March 2010. In August 2015, my cancer returned. In October of 2015, it was necessary to have a catheter placed in my stomach to be able to drain the fluid. The cancer was causing build up each week in my abdomen. I presently only receive a Social Security Disability check each month. Without PSI's help, I would have had to spend hundreds of dollars buying the bottles I need. I am very thankful for PSI's assistance and thank God for you!

Very sincerely,
PSI Patient

Dear PSI:

Thank you so much for all you do! I have been a recipient of your services since August of 2013 and do not know what I would do without you. I have Type 1 Hereditary Angioedema. My daughter has been showing symptoms of my illness, so while she was experiencing abdominal indications, I brought her to my HAE doctor for a visit and blood tests. Thank you, once again, for everything you do for us who are in need!

HAE Patient

Dear PSI staff and donors:

My husband passed away in March. I would like to express my heartfelt appreciation to all of you for making a difficult journey easier. The copays that you paid for his pain management would have been financially very stressful, if not impossible, for us. To provide pain relief for someone is no small thing. The worst part of this disease was seeing him in pain, so I want you to know what a gift you provided both of us by helping us obtain the medication that eased the pain. God bless you and thank you.

Warm regards,
PSI Cancer Opioid Patient

Dear PSI,

Many thanks for sharing your monthly updates with me. They make me feel like part of the PSI family. I will always be grateful for your help. May God bless you!

PSI Patient

Dear PSI:

I wish to express my most sincere appreciation for the help you provided to my mother who was told the operation to remove the GIST from her stomach was successful.

The funds you provided to pay for her medication prior to surgery, helped to reduce the size of the tumor and allowed it to be removed by "keyhole" type surgery.

Thank you from the bottom of my heart for your assistance. You are a very noble and amazing nonprofit organization.

GIST Patient

We Want to Hear from You!

If you would like to have a testimonial about your experience with PSI highlighted in an upcoming newsletter, please contact

Mandy Herbert by e-mail at
unneedpsi@unneedpsi.org

** PSI has obtained consent to disclose patient names and stories in all literature and marketing materials. Patients who wish to share their story and/or image are required to sign a legal authorization form granting permission. A patient may revoke their authorization at any time by notifying Patient Services, Inc. in writing.*

Wrapping Up 2015

By Art Wood, Senior Vice President, Marketing and Development

If you are like me, you always like to end the year feeling as if you have accomplished something worthwhile. I am glad that I can look back on 2015 and remember those patients whom I've met at conferences or on the road who have told me what a lifesaver PSI has been for them. I've talked to parents who have described how their child would not have had his/her treatment were it not for PSI. I've talked with husbands and wives who have told me that they would not be around to see another year if it hadn't been for PSI (as they would not have been able to afford their therapy). I'm thankful that I am in a job where I can go home at the end of the day (and the end of the year) realizing the positive impact that PSI has had on so many lives.

Much of the acclamation really belongs to our generous donors. I find that most of our donors have such a heart for patients and do everything they can to ensure that the donations are in place in order to sustain the assistance programs. This is quite a feat as we currently have over 51 different assistance programs in about 24 different diseases with a total budget of around \$95 million. As you can imagine, it is a challenge for the gatekeepers at our donor companies to advocate for, and secure, that kind of funding in difficult economic times!

As we move into 2016, the needs continue to increase, and our requests to donors continue to increase as well. As of this writing, we anticipate that there will only be a couple of programs which will see

some change next year, but we seem to have donation commitments allowing us to continue providing assistance for most of those coming to us asking for help in order to continue therapy. It is heartwarming for me to see most of our donors struggle to provide as much as possible to ensure that patients receive the help they need. Of course, we would like to help ALL who come to us, but we feel that we maximize the impact of the donations received to ensure that as many as possible are served.

If you are a patient whom PSI has helped, we continue to encourage you to write to your manufacturer, specialty pharmacy, or advocacy group and thank them for supporting PSI (or encourage them to support PSI if they are not currently doing so). If you are one of our donors, we sincerely appreciate your support for these patients, and know that your efforts in budgeting for this will be greatly rewarded! I am writing this as we move into the end of the year and the holiday season.

It is a season where we open our hearts to others and find ourselves a little more generous to the needs around us. May each of you experience the blessing of this season throughout the year as we turn our hearts to helping one another!



Art Wood

Earn Money to Help Support PSI Programs, Just by Searching the Internet!

What if PSI earned a penny every time you searched the Internet? Well, now it can! PSI is a designated charity with **GoodSearch.com**. GoodSearch is a new Yahoo!-powered search engine that donates half of its advertising revenue, about a penny per search, to the charities its users designate. Use it as you would any search engine, get quality searches from Yahoo! and watch the donations add up.

Just go to **www.goodsearch.com** and be sure to enter Patient Services as the charity you want to support in the field labeled "Who Do You GoodSearch For?" After entering PSI as the charity of your choice, feel free to search away. The money raised through GoodSearch will be used

How to GoodSearch

1. Log on to **www.goodsearch.com**
2. Enter "Patient Services" in the field labeled "Who Do You GoodSearch For?"
3. Search Away!

to support our programs and will help us serve more chronically ill patients. As with any search engine, outside advertisers may leverage your searching habits to tailor ads to your interests. Please note to use this site honestly. Fraudulent searches will result in PSI being delisted.

GoodSearch

Raise money for your favorite charity or school just by searching the Internet or shopping online with GoodSearch!

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