



PATIENT SERVICES INCORPORATED

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

Doing the Work of the Angels

By Dana Kuhn, Ph.D., PSI President

There is a proverb which says, “No good deed goes unpunished.” The meaning is: actions intended to bring kindness to people often go unappreciated or are even met with outright hostility. PSI was built upon bringing kindness, relief, financial stability, and better health outcomes to people challenged with the access and affordability of health care. The passion behind the creation of PSI was fueled by personal tragedy and financial devastation, and the desire that no person should live with the challenge of a chronic disorder without help.

In the past 27 years, over a quarter of a million patients and their families have experienced kindness and financial relief to their health challenges from PSI. Because of PSI, at least seven other charitable non-profits similar to PSI have also helped hundreds of thousands of people, literally totaling millions. Together, we have saved millions of lives from untimely deaths, financial devastation, and from increasing taxes on hard working American families. Instead of meeting these charities with outright hostility, these charities should be praised for the work they are doing.

Adversely, there exist entities who meet this kindness with outright hostility. There are media outlets that ignore the plight of the patients and direct their anger toward what they call “Big Pharma” and blame non-profit charities for the increased prices of drugs. That’s absurd. Non-profit charities have nothing to do with setting the prices of drugs. There are entities that place barriers between you and being able to obtain your sustaining treatments. These entities price your premiums and copayments



beyond your financial capabilities, so you are forced to either relinquish your health insurance or eventually be forced into bankruptcy. There are entities that look at your health condition as an economic risk and really don’t want you on their plans. That’s right, money in their pockets is worth more than your life. These entities are the special interest groups that lobby our government to make decisions against your health care.

The truth be told, instead of taking responsibility for access and affordability for health care, these entities are “passing the buck” and blaming non-profits for trying to find solutions to a derisory health system which they created! Non-profits are the only ones standing up to protect patients by trying to ensure patients have access and affordability to health care through solution-oriented programs. PSI was created 27 years ago as a “temporary” solution to health care problems until a permanent solution could be found. Guess what? With all the brilliance of the entities referred to above, no solution has been found in 27 years. Instead, these entities continue to do the same things over and over again, expecting a different result. This is what a brilliant scientist, Albert Einstein, referred to as “insanity.” Non-profits have provided a “sane” temporary solution, which these entities are now attacking with outright hostility.

Fourteen years ago, PSI was granted a United States Office of Inspector General Advisory Opinion allowing PSI to accept donated dollars and use them independently to assist patients with premium and copayment assistance. At that time our government had the “brilliance” to understand

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PSI Launches Campaign to Protect Non-Profit Patient Assistance Programs

Dear Friends of PSI,

We are pleased to announce that PSI has brought together leading patient advocacy organizations to launch the **Marketplace Access Project (MAP)**, a campaign dedicated to protecting non-profit premium assistance for patients living with chronic and life-threatening diseases.

Federal regulatory guidance, issued by the U.S. Centers for Medicare & Medicaid Services (CMS), is prohibiting charitable organizations from helping Americans pay their health insurance premiums, and keeping essential treatments and services out of reach for many of those most in need. As a result of this harmful guidance, health plans across the country are denying coverage to patients with expensive – yet devastating – conditions from their plans, undermining the intent of the Affordable Care Act (ACA) and unraveling the safety net patient assistance groups have worked so hard to create.

To address this oversight, MAP is advocating for bipartisan legislation, the Access to Marketplace Insurance Act (H.R. 3742), which would secure non-



MARKETPLACE ACCESS PROJECT

profit premium assistance for patients enrolled in qualified health plans.

If you'd like more information about MAP, visit www.marketplaceaccess.org. Follow MAP on Twitter ([@AccessProjectUS](https://twitter.com/AccessProjectUS)), and on Facebook at www.facebook.com/marketplaceaccess, or by using the hashtags [#HR3742](https://twitter.com/HR3742) and [#LetCharitiesBeCharitable](https://twitter.com/LetCharitiesBeCharitable).

Thank you for continuing to support PSI as we lead this critical campaign to ensure health care coverage that works for everyone.

Sincerely,
Dana A. Kuhn, Ph.D.

Doing the Work of Angels *Continued from page 1*

there was a problem and recognized PSI's model as a solution, thus rendering us an Opinion. PSI has been operating under that Opinion and compliantly evolving with the changing health care laws and rules in order to continue to provide a short-term solution until permanent solutions can be found.

So, why are PSI and other non-profits being met with outright hostility? Because all these entities cannot figure out a solution and are actually taking their anger and inadequacies out on those who are doing good. On the outset of the solution that PSI has offered for all these years, our legal representatives and government made statements that "PSI is on the side of the angels." Recently, while at lunch with a sensible person observing all this chaos, the statement was made that "PSI was doing the work of angels." I leave this thought with you. If PSI and all the other non-profits are doing the

work of the angels, what work are the entities doing who are meeting us all with outright hostility?

CALL TO ACTION

We need to hear your stories. How has PSI helped you or your family over the years? As opportunities arise, PSI will contact you to assist us in promoting our mission in this world. Please share your story with us by sending it to advocacy@uneedpsi.org.

With much appreciation,

Dana A. Kuhn, Ph.D.

President and Founder
Patient Services, Inc.



PSI-A.C.C.E.S.S.[®] – *An Advocate for Patients' Rights*

For over 25 years, the A.C.C.E.S.S. Program has been providing free legal representation to people seeking federal disability benefits for certain rare chronic conditions. Founded in 1989 by the late Rachel Warner, a non-lawyer whose husband was a hemophiliac, **Advocating for Chronic Conditions, Entitlements and Social Services (A.C.C.E.S.S.)** grew and offered our services to not just the bleeding disorders community, but also to those with primary immune and Alpha-1 Antitrypsin Deficiency. In 2009 we were privileged to join the PSI family, and today we continue to carry forward our legacy of hope as PSI-A.C.C.E.S.S. In 2013 we launched our **Legal Support Hotline** (877-851-9065) to help not only with disability issues, but also with questions related to health insurance, medical leave and workplace accommodations.

We have been able to help many hundreds of people navigate the maze of laws and regulations that can assist them in maintaining financial independence and peace of mind. Now it is our turn to ask for your help. Over the years, our caseload has grown. Meanwhile, the average wait time to have a disability claim adjudicated has gone up, and the national rate at which those claims are approved has been steadily declining. It is thus more important than ever that we secure donors to support our efforts.

And now I am going to let some of our clients argue our case for us. These excerpts are taken from their letters, and explain why what we do means so much.

“Being sick and unable to work is stressful enough, but going through the disability process would have been devastating without PSI’s help.

I am grateful to the sponsors who fund this much-needed service.

I pray that it will continue to be funded.”

PRIMARY IMMUNE DEFICIENCY CLIENT (ARIZONA)

* * *

“Words cannot express how grateful I am to everyone at PSI-ACCESS in helping me get disability. I am not good at stressful things, and they took on all the stress for me. I thank PSI-ACCESS from the bottom of my heart.”

ALPHA-1 ANTITRYPSIN DEFICIENCY CLIENT (IDAHO)

* * *

“The PSI-ACCESS team began the appeal process immediately, kept me informed, and took care of the necessary paperwork. It was a long process, but the staff made me feel like I was one of their family. I highly recommend them because they made me feel like a person, not a number.

If it wasn’t for PSI, I would have lost everything, and I pray they will be able to continue this wonderful mission.”

HEMOPHILIA CLIENT (ALABAMA)



PSI-A.C.C.E.S.S. has been able to help many hundreds of people navigate the maze of laws and regulations that can assist them in maintaining financial independence and peace of mind.

PSI Leads the Effort to Protect Patients and Needs Your Help

By James Romano, Director of Government Relations

For the last two years, PSI has led the efforts to overturn the Centers for Medicare and Medicaid Services (CMS) Interim Final Rule on Third-Party Premium Assistance. CMS is allowing health insurance carriers in the state and federal Marketplace plans, created as part of the Affordable Care Act, to prohibit third-party premium assistance from charities like PSI. Insurance plans in 38 states have implemented this rule as a means of removing patients with rare, chronic and catastrophic illnesses from their coverage. This policy is tantamount to a new pre-existing condition on the patients we serve. PSI has worked closely with Congressman Kevin Cramer (R-ND) to introduce a legislative remedy to this issue, *H.R. 3742, The Access to Marketplace Insurance Act*.

This spring, PSI hosted its annual advocacy day in Washington, D.C. The PSI Board of Directors, Staff and patient advocates from across the United States canvassed Capitol Hill obtaining co-sponsors for this important legislation. The Access to Marketplace Insurance Act currently has 68 co-sponsors in the House of Representatives. The Cramer bill would mandate that health insurance carriers in the Marketplaces accept third-party premium assistance from nonprofit organizations, places of worship and civic organizations.

As part of the PSI Advocacy Fly-In, PSI honored our legislative champions including Congressman Cramer, Congresswoman Chellie Pingree (D-ME) and Congressman David Brat (R-VA) with our PSI Patient Champion awards. PSI also presented Mr. Tony Castaldo, President and Founder of the Hereditary Angioedema Association, with the 2016 PSI President's Award. Tony has been a valued supporter of PSI for many years.

Ultimately, the issue at stake is whether private charities should be able to help Americans get the adequate coverage and care that they need. If insurance carriers can dictate how a consumer obtains the funds to pay their insurance premium or where they can turn to receive help, the lives of patients will be adversely impacted. PSI still needs your help to overcome this onerous interim final rule. We need as many congressional co-sponsors as possible. We can only obtain them with your help. If you would like to assist PSI in our campaign, please contact me directly at jromano@unneedpsi.org.



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The issue at stake is whether private charities should be able to help Americans get the adequate coverage and care that they need.

This past spring the PSI Board of Directors, staff and patient advocates canvassed Capitol Hill seeking co-sponsors for *The Access to Marketplace Insurance Act*.



PSI Board Chair Gary Cross, Congressman Bruce Westerman (R-AR), Congressman David Brat (R-VA), and PSI President Dana Kuhn



PSI's Jim Romano, Congressman Kevin Cramer (R-ND) and Dana Kuhn



Congressman Bob Gibbs (R-OH); PSI Board members; and Mr. Tony Castaldo, president of the Hereditary Angioedema Association



PSI Board with Congressman John Fleming (R-LA)



Dave Obrochta, Mark Hobracczk, Congresswoman Debbie Wasserman Schultz, Ed Burke, Dana Kuhn and Tom Nuttle



Letters From PSI Patients



Dear PSI,

I just wanted to thank you for another year of helping taking care of my daughter. Your organization has been a tremendous blessing to our family, and I want to express how much we appreciate what you are doing for her with the premium assistance program. Just as an update, my daughter is now in her second year of college and is pursuing an art degree, which she intends to use to teach art to children in a lower income area of Tulsa. She has a heart for helping kids recognize and develop the creativity she believes every child has been given. She's pretty awesome, if you ask me!

Thank you again for the work you do to support patients like my daughter!

Mother of PSI Patient

Dear PSI,

You will never know the tremendous support your organization has provided to our family. My daughter has been in and out of the hospital the past 7 months due to complications with her medication. Whenever she goes in the hospital, it is extremely cold, and this induces her hereditary angioedema. If we did not have the support that is given to us from PSI, my daughter could have been in life-threatening situations each time she was in the hospital. A simple "thank you" does not say enough, but adding "praise God" makes it far more powerful in knowing you were there for us. Again, "Praise God and Thank You" for all your support!

Sincerely,

PSI HAE Patient

Dear PSI,

I would like to extend my heartfelt thank you for your co-pay assistance. I have CML and am on a super expensive chemotherapy drug, which I take daily. The drug has a very high cost, in the \$9000.00 range for a 30-day supply. Being on Social Security, my budget could not make the monthly co-pay. With this drug, my CML is in check.

Once again I thank you for your help.

PSI CML Patient

Dear PSI,

It was with great excitement and relief that I learned of your approval to assist with my prescription. After 61 years of struggling with kidney stones, I have been free of those "little critters" since being placed on a life-saving medication in 2008. Enabling me to continue that medication is truly gratifying. To you and your staff at PSI, thank you for your assistance and support.

Gratefully,

PSI Kidney Stones Patient

** 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.*

Dear Folks at PSI,

I have started a journey to health with assistance I never knew existed. I am so thankful and humbled by the help that has been provided to me. I was totally shocked at the cost of this type of medicine. I worked in a clerical position in the medical field most of my working life. I was aware that some medications were costly, but I guess it just never hit home. A diagnosis of IPF was frightening, and then I was told of a wonderful medication – excitement – then the cost – death sentence – out of my reach. Thanks to amazingly wonderful folks like you, I have a chance at life. There is no price on that. I am very grateful and humbled.

Many thanks,
PSI IPF Patient

Dear PSI,

I am a GIST patient, and I have recently retired and just went on Medicare. I had excellent coverage prior to Medicare and was very concerned about the donut hole (\$3,200) and copays for my medication, which could be \$1,500 to \$4,000 per month. My prescribed medication is a life-saving drug but very expensive!

I applied for PSI assistance several months ago and hoped it would reduce the cost of the cancer drug. I filled my first Rx recently and expected to clean out my old HSA account with thousands of copays and deductibles. However, after the pharmacy ran my insurance card and my PSI payment card, I was completely covered – what a pleasant surprise! I am very grateful and want to thank you for your assistance!

PSI GIST Patient

Dear PSI,

Enclosed with this letter is a contribution to your organization. My husband was a recipient of financial assistance from PSI a number of years ago when he was first diagnosed with multiple myeloma and was faced with monstrous medical bills. I am pleased and thankful to report that his disease continues to be in remission, but we still remember how much your assistance meant at that very difficult time in our lives. We are happy to be in a position now where we can at least partially repay your generosity. Please know that we will forever be grateful for your support and services!

PSI Oncology Patient

Dear PSI,

I wanted to take a moment to extend just how much I appreciate all that you and the ACCESS program have done. I know that there isn't a chance that I could have muddled through all of the disability documents, more importantly, the hearing. Your kindness, knowledge, and support are deeply appreciated. Thank you to your staff as well.

Sincerely,
PSI Bleeding/ACCESS 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 uneeedpsi@uneeedpsi.org



Patient Assistance: Broader than You Realize

By Art Wood, Senior Vice President, Marketing and Development

The budget was finalized in January, and we moved into 2016 with increases in most of our programs. We appreciated the donors who increased their donations proportionate to the growth of the patient population over the past year. Many find it surprising that the costs increase at least ten percent annually simply to support *current patients on service* (depending on the program). Some of these increases come from the patients who have come on service throughout the previous year. Some of the costs come from increasing prices (increases in insurance costs, drug costs, inflation costs, etc.). In addition, if we intend to keep the programs open during this year in order to *add new patients*, the increases will be much greater.

Many of our patients write us letters to tell us how they would (literally) not survive without the help of PSI. It is always encouraging to us to work with donors who truly have a grasp of the financial needs of the patients, and are also aware of the need to continually advocate for these vulnerable populations. When people talk to me about PSI, they are surprised that we provide assistance beyond financial support. It has been built into our DNA to advocate for these patients. Over the years, PSI has worked hard with state and government agencies to address the challenges for patient access. You will read at other places in this newsletter about

our bill currently in Congress (HR 3742), which will enable PSI and other non-profits to provide assistance to patients who are being insured by the Marketplace Exchanges. Most don't realize that a number of insurance plans across the USA are blocking non-profits from helping these patients. This bill would allow this possibility. Last year, PSI advocated with the Office of the Inspector General and the Rare Disease Caucus of Congress to allow more access to therapy for Rare Disease populations which was being drastically limited. These are but a few examples of how PSI seeks to help patients access their treatments.

Thank you patients for your letters throughout the year which encourage us to continue to do this work. Thank you for letting the manufacturers who provide your treatment know how much you appreciate them. Thank you donors for providing these lifesaving therapies and for seeing the need to support organizations like PSI in order to compliantly provide the urgently needed assistance to patients. We will be here, as long as the need continues, helping to ensure that patients without hope will once again see that they are not forgotten.



Art Wood

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.

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