Congress Must Ensure Charities Remain a Safety Net for Patients

By Dana Kuhn, Ph.D., PSI President

As Congress gets ready to reform the Affordable Care Act (ACA), the health insurance industry has set its sights on an unlikely target: nonprofit charities that provide premium and co-pay assistance to patients in need.

Precisely because these charities step in and help chronically and terminally ill patients stay on and use their private insurance, health insurers want those patients off their rolls. Congress must act to ensure that charities remain a vital safety net for these patients.

Even today, both private insurance and Medicare leave many Americans behind, making it virtually impossible for the chronically ill to maintain the health coverage they need. While the private insurance market covers those with pre-existing conditions, there is no assurance these patients can afford that insurance or their medications.

For example, chronically and terminally ill patients often are prescribed medications that are not on the lower-tiered plans, mostly because less-expensive generic alternatives do not exist. Thus, these patients must pay the higher premiums of gold and platinum plans in order to secure this coverage.

But that still does not suffice, as these higher-tiered plans have large deductible and coinsurance requirements that force these patients to pay substantial out-of-pocket costs on top of their premiums. All told, these patients can pay as much as 30 percent of their gross incomes on their medical care.

The financial reality for Medicare-insured patients is equally bleak. Medicare Part D beneficiaries face the “donut hole” – a certain expense threshold beneficiaries reach that requires them to pay 50 percent of their prescription drug costs. This, too, forces patients to make terrible choices between food and shelter or lifesaving medicines as they are often on fixed incomes.

Congress, however, can fix this problem. First, it could seek reasonable solutions to make the coverage gap less burdensome. However, the incoming Congress is unlikely to support additional federal spending given its desire to pare back the ACA. A more realistic approach would be for Congress to pass legislation to empower charitable organizations to support these patients through premium and co-pay assistance, a path that would not cost taxpayers a cent.

Almost 30 years ago, I founded the first charity of its kind to help patients in need pay for their insurance premiums and their medication. Today, nine charities provide $1 billion in annual assistance to over half a million Americans. Without this charitable support, many of these patients would lose their homes, skip or not take appropriate drugs, have less food on their tables, or be forced down the path of bankruptcy. Indeed, many couples have involuntarily divorced so that sick children could qualify for Medicaid.

Why is Congress needed? Because insurance companies are targeting these charities, at both the federal and state levels, seeking to ban this charitable assistance and force patients into federal programs where taxpayers must foot the bill.

For insurance companies, it is all about their profits. Nonprofit, charitable support of these patients enables them to stay on their employer-provided or ACA-obtained private insurance and afford the actual medications their doctors prescribe.

Insurers don’t want that. They want to force these patients toward insolvency, so that they are forced onto
With over 140 co-sponsors and broad bipartisan support, the Access to Marketplace Insurance Act (H.R. 3742) would let patient assistance charities be just that – charitable.

If enacted, this bill would simply add nonprofit charity assistance to the list of existing, acceptable third-party premium assistance programs, reversing the insurers’ recent efforts. We should recognize that outlawing denial of coverage for pre-existing conditions is a necessary consumer protection – a provision of the ACA that President-Elect Donald Trump agrees should remain intact. Being unable to afford your insurance and medication is just another invidious form of a pre-existing condition.

The time is now to shine a light on those who have fallen through the cracks of our healthcare system and support them. Most importantly, the time is now to stop insurers from removing a vital safety net for the most desperate patients.

Dana A. Kuhn, Ph.D.
President and Founder
Patient Services, Inc.

This opinion was written by Dr. Dana Kuhn and appeared in the January 17, 2017, issue of The Hill. The views expressed by contributors are their own and not the views of The Hill. To view this article online, go to The Hill: http://thehill.com/blogs/pundits-blog/healthcare/314662-congress-must-ensure-charities-remain-safety-net-for-patients

Advocacy Day Reception
Show your support for patients with rare and chronic conditions

Save the Date | April 26, 2017

Patient Services, Inc.
501(c)(3) non-profit organization
PSI Is Fighting for Healthcare Access for All Patients

By: James Romano, Director of Government Relations

America stands at a unique moment in our history with a new administration and a new Congress, one not seen in many years. PSI still stands ready and able to assist patients and their families with the unaffordable costs of health insurance premium and treatment coinsurance. PSI is continuing its push to preserve this assistance in this new Congress, the new administration, and with state governments. Last year PSI led the effort to protect premium assistance through H.R. 3742, the Access to Marketplace Insurance Act. The legislation was introduced in response to a regulation that was promulgated by the Centers for Medicare and Medicaid Services (CMS) in 2014. This rule, which has been reaffirmed several times by CMS, allows health insurance providers to prohibit third-party assistance in the health plans created by the Affordable Care Act. Through the hard work of patients, patient groups and PSI, we were able to acquire 147 cosponsors in a very partisan political environment.

With a new Congress, the legislation will have to be re-introduced and our champion Congressman Kevin Cramer (R-ND) has agreed to do that. There will be changes made to the healthcare system over the next several years, but access to charitable assistance must be preserved. However, the health insurance industry is lined up against this proposal. Instead insurance providers want to push patients onto public insurance options like Medicare and Medicaid. Insurance companies simply do not want to provide coverage to patients with rare diseases, chronic illnesses and catastrophic conditions. This is a bottom-line issue of profits over patient lives and quality of life. PSI and the patients we serve need to show Congress and the new administration that charities and charitable assistance are so very integral to the lives of Americans. PSI will continue to fight restrictions that limit our patients access to treatment. You can become involved with our campaign.

PSI will once again be hosting our Advocacy Day and Congressional Reception this year on Wednesday, April 26th, in Washington, D.C. I urge you to remain involved with our campaign to overturn this rule and to prevent further limitations of patient assistance. In closing I will leave you with one of my favorite lines from the movie, “The American President:” In this country it is not only permissible to question our leaders – it’s our responsibility.” Please join us to make your voices heard. For more information, please contact me at jromano@uneedpsi.org.

New and Exciting Features in 2017

By Tiara Green, MSEd, Director of Operations

PSI is proud to introduce new and exciting features for our patients. Beginning in January 2017, PSI implemented use of a prepaid assistance card for eligible programs and assistance types. This allows patients to make direct payments for eligible healthcare-related expenses according to the program guidelines. Patients who are eligible for this payment option received such notification in the mail.

In March 2017, we will be launching another payment option for patients to receive reimbursements for eligible services directly into their bank accounts. This allows PSI to provide patients with a simple yet quick way to receive assistance. Information on how to register for this payment method will be sent to patients at the beginning of March.

In March 2017, PSI will be launching another payment option for patients to receive reimbursements for eligible services directly into their bank accounts.

As we approach a very busy time of year, we encourage patients to access their PSI Patient Portal to apply for assistance or review information regarding their existing PSI assistance. Through the portal, you can securely view details about your assistance account online 24 hours a day, 7 days a week.
Save the Date for PSI’s Annual Evening of Hope

By Mandy Herbert, MBA, Director of Community Outreach

PSI is pleased to announce that we will host our annual “Evening of Hope” in Washington, D.C., on Wednesday, October 25, 2017, at The Newseum from 6:30-10:30 p.m. It is our hope that industry, patient support groups and those interested in learning about how PSI restores hope and health to chronically ill communities will consider attendance at this educational event.

As in previous years, PSI will honor those who have gone above and beyond to help those within the rare disease community. Additional highlights of the evening will include a cocktail hour, seated dinner, recognition of event sponsors, raffle, an address by PSI President Dr. Dana Kuhn, educational updates, live patient testimonies, and more.

Details regarding sponsorship opportunities can be found below. If you are interested in sponsoring this memorable event or learning more about sponsorship opportunities, please contact Mandy Herbert, Director of Community Outreach, at PSIDevelopment@uneedpsi.org.

Keep an eye out for an email from PSI with further save the date instructions and ticket purchase details. Our team looks forward to seeing you in October.

---

**GOLD SPONSORSHIP**

$10,000

- Two premier tables of eight (8)
- Opportunity for corporate leader to present a 30-second video or presentation
- Group photo opportunity with foundation executives and honorees
- Sponsor logo, with hyperlink to sponsor’s website, on PSI’s website advertising event
- Priority placement of a full-page ad in the event program
- Formal recognition from the stage during evening program and on-screen recognition

**SILVER SPONSORSHIP**

$5,000

- One premier table of eight (8)
- Priority placement of a half-page ad in the event program
- Sponsor logo, with hyperlink to sponsor’s website, on PSI’s website advertising event
- On-screen recognition during evening program

**BRONZE SPONSORSHIP**

$1,000

- Four (4) tickets to event
- Quarter-page ad in the event program
- Sponsor logo on PSI’s website advertising event
- On-screen recognition during evening program

All sponsorships above include:
- Sponsor listing in save the date and formal invitation
- Sponsor name to be listed in press releases regarding event
- Listing in PSI’s 2017 Annual Report
 PSI ACCESS Helps Navigate the Complex Maze of Health Care Coverage

As we go about taking care of our families and managing our careers, it’s easy to forget that many of the choices we make can have an effect on our health care coverage. PSI-ACCESS is here to assist you when you have questions about maintaining your benefits.

We have been helping people like you navigate the often complex maze of state and federal laws and regulations governing disability, job accommodation, medical leave, insurance appeals, and eligibility for or continuation of benefits for more than 25 years.

Based on some of the most frequently asked questions that we have received, we developed a list of situations where you may need to consider and discuss your options. The list has changed over the years thanks to the ever-shifting kaleidoscope rules that can impact access to care. Read our revised reasons to call PSI ACCESS on the next column:

The one thing that is certain is change: as we move forward, there are sure to be changes in the rules that can be triggered by life events. We encourage you to call PSI-ACCESS toll-free at (888) 700-7010 when you need help understanding how life changes may affect the availability of health care coverage or other important benefits for you and your family.

1. I lost my job.
2. I’m looking for work.
3. I got a new job.
4. I need help to do my job.
5. I need to take time off from my job.
6. I’m no longer able to work.
7. I’m about to lose my health insurance.
8. I don’t have health insurance.
9. I am getting married.
10. We just had (or adopted) a child.
11. My child has lots of medical bills that I can’t pay.
13. My child is leaving for college.
14. My child is about to turn 26.
15. My spouse stopped working.
16. I’m getting a divorce.
17. My spouse passed away.
18. I’m moving.

January 4, 2017

To the staff of PSI ACCESS:

I just wanted to give my personal thanks for your help in getting my disability coverage. After I was first denied, I was at a loss of what to do. It had been 5 months since I had applied, and I was unable to work. I had no idea how to choose a disability attorney in my area or what the cost would be.

Luckily I had saved my newsletters from The IDF Advocate and remembered an article explaining the process to file for disability. I located the article and called your 800 number for assistance. You were not only friendly but extremely helpful. I was especially relieved to find that my attorney fee would be waived because of my rare chronic condition – primary immune disorder. With your help, my disability appeal was filed, and I would be contacted if any additional information was needed. As my hearing date got closer, I then received a call from Terry Staletovich, my disability attorney, who explained the procedures of the hearing.

Although I was nervous, I took Terry’s advice in answering the court’s questions and felt that the hearing went well. A while later I received an official letter of approval for disability from the court. I was not only happy but extremely relieved that the process was near completion. Since that time I’ve had a few questions, and your staff has always been friendly and helpful.

I would highly recommend PSI ACCESS to anyone seeking to get disability coverage and wish to say thanks to all who have contributed to their cause as patient advocates.

Sincerely,

PSI ACCESS Patient
Dear PSI,

Recently I was out of work for a few days due to my grandmother passing away. Four years ago she was diagnosed with Pulmonary Fibrosis. I just want to take a minute and thank PSI, because from 2014-2015, PSI assisted my grandma and made it possible for her to be with us a few years longer. What you do for your patients truly does make a difference in their lives and the lives of their families. I am grateful for all that you have done, and I am proud to say that I’m part of such an amazing organization. Thank you.

Pulmonary Fibrosis Patient

Dear PSI,

I want to send you a note to tell you what a difference your program has made in my life. I was diagnosed with Pompe Disease in October. For the last year, I have had to shift to part-time work because of the effects of the disease. Once I received the diagnosis, I worried about whether I could afford to get health insurance and pay my medical bills if I could only work part-time. Insurance premiums alone would eat up nearly half of my net income. I considered filing for disability, so that I could eventually qualify for Medicare, but I love my work and want to keep working. The support offered by your program now makes it possible for me to keep working. I cannot tell you what that means to me.

Thank you!

Pompe Disease Patient

Dear PSI,

Believe me, I love the opportunity to let you all know, once again, how much I appreciate all of you and the work you do. I am in my sixth year of Chronic Myeloid Leukemia. I am alive, thanks to you and your donors. I do not take this life for granted. I remain humble and thankful. I try to keep this life full.

I still tutor 10 hours per week. I still sing and play alto saxophone entertaining in assisted/independent living facilities, nursing homes and private parties. I still stay involved with family and friends. I try to give back the gift of the day. I am 77. I hope to live more years yet. Without your assistance with my medication, I would not be able to do so. Thank you so much for the help you give me.

Sincerely,

CML Patient

Dear PSI,

I want to thank you with all my heart for your help with the copay for the medication that keeps me alive. I have advanced Gastrointestinal Stromal Tumors, and I am on Medicare. Because of your kind help, I am able to live one day at a time, taking care of my health, and dealing with this cancer without worrying about the cost of this drug. So far I have had 5 months of life, so precious without the worry, so there are no words enough to express my gratitude.

Thanks,

GIST Patient
Dear PSI,

I would like to thank everyone who is working for such a valuable organization. PSI has helped three generations in my family as we all have Hereditary Angioedema. Without the help and understanding we receive from PSI, we would not be able to get our lifesaving medicine. I would like to thank you again for all that PSI has done for my family. May GOD bless you all!

HAE Patient

Dear PSI,

I wanted you to know how grateful I am to have received your assistance that aided in extending the life of my husband. Without it, we would not have been able to celebrate our 50th wedding anniversary. Over the past months my husband was able to visit with both of his children and see them in their brand-new homes with their families. I was also able to get him to the beach. I spoke of your organization at his memorial asking that any donations being made in his name be sent to PSI. Thank you so much for helping us have this time together.

Sincerely,

Idiopathic Pulmonary Fibrosis

Dear PSI,

I have been fortunate enough to be part of your wonderful program since 2013 when it helped to pay for my CML medication. This was a great stress reliever! Last year I was diagnosed with IPF and was prescribed another very costly medicine. Again, PSI has “saved” us. Thank you for all you do to make life easier for people when they are most vulnerable. God bless you and your donors.

CML & Idiopathic Pulmonary Fibrosis

Dear PSI,

What can I say? Thank you. Thank you for a year to watch my children develop and grow in their endeavors. Thank you for a year to enjoy the love of my wife. Thank you for a year to appreciate the goodness of the folks at PSI and the donors who have made this year possible. The generosity of PSI has kept people like me from making financial choices that would be disastrous.

Once again, thank you.

CML 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 email at uneedpsi@uneedpsi.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.
Swimming Upstream
By Art Wood, Vice President

If you read last fall’s newsletter, it mentioned the phrase “swimming upstream.” Due to an increasingly restrictive regulatory environment, it has made it very difficult to have the discourse between donors and PSI, which most regular businesses enjoy. This means that donors are less informed about the patient populations, less informed about the financial budgets, and less informed about the challenges of the patients in the programs. On the other side of that equation, it means that we receive less information from them as well. Can you imagine two businesses having normal business interactions but not able to really communicate with one another?

It certainly makes it more challenging to ensure that everything is in place for helping each of the patient populations with which PSI deals. In spite of that, we work diligently to ensure that these assistance programs are adequately funded and patients are receiving the help they need. As of this writing, most of the programs have been set for the year. There are some companies that continue to struggle to finalize their budgets by the end of the year, but those companies will usually let us know by early January at the latest so that patient assistance is not interrupted. If you are a donor, and have not yet made your commitment, please let us know ASAP so we can best plan for the patients we will be able to help for the remainder of the year.

In light of the uncertainty of the new administration in Washington, D.C., patients are coming to us in increased numbers for help with their treatments. We continue to hear that if PSI did not help, they would (literally) not survive as they couldn’t afford their therapies. We appreciate the donors who are proactive in increasing their donations for the year realizing that the demand increases. I am often amused by those who want us to keep the programs fully open to all referrals, yet fail to increase their donations (and sometimes even in the face of decreasing the donation). PSI works very hard at being good stewards of the funding provided to ensure that the most patients possible can be assisted, and we appreciate the generosity of all those who donate to help these patients.

We expect it to be a challenging year; however, we look forward to seeing lives changed through the intervention of PSI. Hopefully, we will cross paths at one of the patient conferences during the spring or summer so we can visit in person. If you attend one of these, please make a point to come see us. We always enjoy hearing your stories.

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 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.

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!