Teaching Patients Self-Advocacy

United States
Jennifer Jaff
Organization type:
nonprofit/ngo/citizen sector

Budget:
$100,000 - $250,000

Website:
http://www.advocacyforpatients.org

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**Disability**
**Health care**
**Health education**
**Wellness**

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**Elevator Pitch**

Concise Summary: Help us pitch this solution! Provide an explanation within 3-4 short sentences.

Chronically ill patients who participate in their own care are more compliant with doctors’ orders and, thus, have better health outcomes. However, many patients do not have the skills to do so. Our project would teach patients how to collect their own medical records, interact with their physicians, and advocate for their medical and insurance needs through a series of training videos.

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**About Project**

**Problem:** What is this project trying to address?

Patients with chronic illnesses are expected to manage their own care — with no training. They do not know whether the law entitles them to a copy of their medical records. They do not know how to research their illness and its symptoms. They do not know how to coordinate care among several health care providers. Indeed, often, they do not even know how to spell the name of their disease. Yet, to be an effective patient, you not only must know all of this, but you must know how to read an insurance explanation of benefits, how to appeal an adverse insurance coverage decision, how to ask for accommodations at work or school, how to ask for family and medical leave. We expect patients to simply know all of this, but clearly, it is difficult and complex, and often becomes necessary in a time of medical crisis. By teaching patients these skills, we can help them to get the care they need.

**Solution:** What is the proposed solution? Please be specific!

Nobody else in the United States works with chronically ill patients nationwide in areas including health and disability insurance, Social Security disability, employment discrimination, family and medical leave, educational equity, and resource location, so nobody has our experience and our perspective. No other organization focuses on the distinct feature that we call "chronicity," which makes chronic illness different from illnesses that are terminal or illnesses from which you recover. Indeed, we are currently gathering and analyzing the data from a year-long NIH-funded chronic illness survey we conducted in partnership with the University of Michigan Center for Managing Chronic Diseases. We would take our experience working with patients, studying patients, and being a patient, and teach other patients -- our peers -- to manage their own...
care and their own lives. What makes our idea unique is that we have a large volume of diverse experience to inform it. We know how hard it can be simply to gather medical records or coordinate care among several physicians. We not only live this ourselves, but we have worked with thousands of patients who have struggled to do so on their own until they found us. We know what the problems are, and we know how to solve them. Nobody else can say that. With all of that background, we plan to create video trainings that patients can watch on the internet to teach them how to be a patient -- how to collect medical records, manage insurance issues, advocate at work and school, and so on.

Impact: How does it Work

**Example: Walk us through a specific example(s) of how this solution makes a difference; include its primary activities.**

We have worked with thousands of patients nationwide. We win approximately 85% of our insurance appeals, including the hardest cases involving rare diseases. We resolve every employment or school-based case without litigation. We have developed web-based tools to instruct patients on how to write their own insurance appeals, and have sold thousands of copies of our book, Know Your Rights: A Handbook for Patients with Chronic Illness. Our impact can be seen in the results we get, or that patients get for themselves upon implementing our advice. But more importantly, our impact is seen in the small donations we receive, and the many notes of thanks we have collected over the years. We are saving lives; our impact is nothing short of that.

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**About You**

**Organization:**
Advocacy for Patients with Chronic Illness, Inc.

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**Section 1: You**

**First Name**
Jennifer

**Last Name**
Jaff

**Email**
patient_advocate@sbcglobal.net

**Website URL**
http://www.advocacyforpatients.org

**Organization**
Advocacy for Patients with Chronic Illness, Inc.

**Country**
CT, Hartford County

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**Section 2: Your Organization**

**Organization Name**
Advocacy for Patients with Chronic Illness, Inc.

**Organization Phone**
860-674-1370

**Organization Address**
18 Timberline Drive, Farmington, CT 06032

**Organization Country**
CT

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**Your idea**

**Country and state your work focuses on**
CT, Hartford County

**Website URL**
http://www.advocacyforpatients.org

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**Innovation**

**Do you have a patent for this idea?**

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**Impact**

**Actions**
Every day, we help a patient find resources -- insurance, a free clinic, tree medications, copay assistance -- anything they need, including food and housing. Every day, we appeal health and disability insurance noncoverage decisions. This year, we built a web-based patient resource center so patients with a whole host of rare diseases could learn to file their own insurance appeals for intravenous immune-globulin. We would like to expand that web-based resource to include video trainings that we can post on our website, as we already have done with our video on Living with Chronic Illness. Our goal is to give patients the tools they need to help themselves, while we continue to help those with the most difficult cases. This grant would allow us to take these action steps now.

While I was writing this, I got an email from Erika who had just finished watching our Living with Chronic Illness Video. She wrote just to thank us. We have helped her today; with your help, we can help thousands of Erika's.

Results
We already train patients to be "professional" patients one-on-one. What we hope to do with this project is to record trainings and post them on the internet so that patients everywhere will have access to our experience and expertise. This will allow us to reach so many more patients annually. In our experience, patients are ready and willing to learn. We have had great success in public speaking and media, but to reach a broader audience, video trainings that we can post on our website would be ideal. We hope to create a veritable army of empowered patients.

What will it take for your project to be successful over the next three years? Please address each year separately, if possible.

In the coming year, we hope to move to commercial office space to make room for our growing staff. Our Board currently is in the process of developing a strategic plan, but as of today, our goal is to hire at least one additional attorney, to develop video trainings that can be posted on our website, and then to conduct a methodical outreach program that will ensure that everybody who needs us can find us.

What would prevent your project from being a success?
Nothing. It will be a success.

How many people will your project serve annually?
1001-10,000

What is the average monthly household income in your target community, in US Dollars?
$1000 - 4000

Does your project seek to have an impact on public policy?
Yes

Sustainability
What stage is your project in?
Operating for more than 5 years

In what country?
Connecticut, CT, Hartford County

Is your initiative connected to an established organization?
Yes

If yes, provide organization name.
Advocacy for Patients with Chronic Illness, Inc.

How long has this organization been operating?
More than 5 years

Does your organization have a Board of Directors or an Advisory Board?
Yes

Does your organization have any non-monetary partnerships with NGOs?
No

Does your organization have any non-monetary partnerships with businesses?
No

Does your organization have any non-monetary partnerships with government?
No

Please tell us more about how these partnerships are critical to the success of your innovation.
Our work with the University of Michigan Center for Managing Chronic Disease has allowed us to gather a tremendous amount of data regarding the challenges faced by the chronically ill in a systematic way so that, once the data is all culled and analyzed, we will be in an even better position to identify those areas in which patients with chronic illnesses need support.

What are the three most important actions needed to grow your initiative or organization?
(1) Purchase the equipment to allow us to create video trainings that we can post on the internet; (2) rent commercial office space (and furnish it) to make room for growing staff; (3) conduct a methodical outreach campaign to ensure that everybody who needs us knows where to find us.
The Story

What was the defining moment that led you to this innovation?

When I realized I no longer could practice trial law on an ongoing basis because of my own illness, I started looking for alternatives, work I could do at home. What I found were communities of patients in desperate need of my skills. I took on an insurance appeal . . . and then a disability retirement appeal . . . and then another appeal. I realized I was answering the same questions over and over again, so I wrote the first version of what now is our Know Your Rights handbook. It wasn't so much a defining moment as it was a process. And now I know that this is what I was meant to do with my life.

Tell us about the social innovator behind this idea.

That would be me. I am 53 years old and have two chronic illnesses, and nothing can keep me down. This work gives me a reason to keep going. When I gave my first live speech to a group of patients and I talked about my experience as a patient, we all ended up in tears, singing We Shall Overcome in unison. I inspire people by what I do to try to do more with their own lives.

How did you first hear about Changemakers?

Through another organization or company

If through another, please provide the name of the organization or company

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