#### Describe your solution.

One of the many unfortunate realities of a cancer diagnosis may be the inability to continue gainful employment. Either the debilitating symptoms of the disease itself, or the effects of therapy and treatment, can derail even the most promising career trajectory. When this occurs patients, their families and caregivers seek out the financial assistance and benefits they may be eligible for in order to make ends meet. At one of the major crossroads of the vast insurance industry and the entitlement benefits system is a much maligned but critically important safety net, the Social Security Disability Insurance program (SSDI). Designed to provide cash assistance to those of working age who are administratively eligible in the event of a total disability – as defined by the Social Security Administration (SSA) – SSDI is a financial lifeline for millions of Americans including over 275,000 workers diagnosed with a disabling neoplasm. The $1,313 average monthly benefit they receive is often their only income but the process to even be awarded such an allowance can be challenging.

As daytime television commercials constantly remind viewers many SSDI applicants are denied, at least initially. And although the reasons for such denials are varied and ripe for political volleying many firms, lawyers and otherwise, are now in the business of supporting the claims of applicants during the two initial administrative process levels and the subsequent appeal hearing before an administrative law judge (ALJ). These attorney and non-attorney advocates are granted access to an applicant’s medical file as part of their case development. It is here that they have an opportunity to inform patients that they may be eligible to participate in a clinical trial that could have a positive impact on their health. The advocacy groups should be given information (literature, online resources) to pass along to their clients about how and why to further investigate their eligibility for trial participation. With the suggestion coming from someone they may already hold in high-esteem (a lawyer fighting on their behalf to access money they need) it may be enough of a nudge to create action.

Indeed only a portion of SSDI applicants hire a representative. And many do not do so until they have been denied twice and are facing the prospect of a long wait prior to appearing before an ALJ. Thus the opportunity to connect these unrepresented applicants with clinical trial information should fall to the SSA and/or the state Disability Determination Services (DDS) agencies who work in tandem to determine an applicant’s eligibility for SSDI at the initial and reconsideration stages. Here we should augment the online SSA SSDI application system to ask if an applicant has looked into joining a clinical trial and provide additional information for uncovering appropriate trials to join. In addition, another form can be added to the paperwork DDS sends out to applicants that is HIPAA-compliant requesting approval for their information to be shared with clinical trial recruiters. Or if online forms and mailed letters are too passive, perhaps adding the question to the call prompts of SSA and DDS staff may aid in causing patients to bring up clinical trials in their conversations with their physician.

#### How will you do it?

I worked in the disability advocacy space for years and know many well qualified people who may be interested in helping. In addition there is already an active organization committed to advocating for the creation of a federally sponsored public awareness campaign that may be able to help. Also a somewhat related bill, Improving Access to Clinical Trials Act, was passed in 2009 and the ongoing 21st Century Cures initiative is working to accelerate the pace of clinical cues.

#### How does it work?

Advocacy organizations and SSA/DDS would utilize their current communication and operations processes to share information about clinical trials with their client base.

#### What does it look like?

An information sharing program between advocacy organizations and their clients to further support their health.

#### How will you implement it?

Through direct outreach to advocacy organizations we would explain what we are trying to accomplish and seek their agreement to share information about clinical trials with their client base. Involving SSA/DDS would take greater effort and require well defined partnerships.

#### Where will you implement it?

This would be a nationwide effort since SSDI is a federal program and the largest advocacy organizations are also national in scope.

#### Who will be involved (stakeholders)?

In the first phase the operational leadership of the advocacy firms will be involved in order for them to pass along the new processes to their staff. The longer term effort of involving SSA and/or the state DDS offices will be more complicated and involve various policy and operations stakeholders. This may require an outside consultancy to assess the situation and lobby for and implement the solution.

#### How much will it cost to create the solution (an estimation)?

Developing collateral about clinical trials to share with patients via their representative or SSA will cost tens of thousands of dollars. However once the call prompts are modified there should be no ongoing cost to the advocacy firms. It would likely be a significant challenge to get SSA/DDS to modify their online and paper applications.

#### How much will it cost to implement the solution (an estimation)?

The major challenge and cost will certainly be to encourage SSA to assist with this effort. It should not be a significant cost to implement it with the advocacy firms.

#### How many people will be impacted?

275,000 SSDI worker recipients currently in payment have a disabling neoplasm. Each month 10% of all new awardees (amounting to 7,200 disabled workers) are granted SSDI as result of a neoplasm, the fourth largest diagnostic group. In addition over 20,000 applicants per month have a neoplasm.

#### How long will it take to create the proposed solution?

A few months for working with the advocacy firms but a year or more when involving SSA/DDS directly.

#### Why will it work? Why is it viable?

This is a logical place to start considering the niche advocacy industry that already exists as well as the fact that by default SSDI applicants have a documented and disabling condition.

It can be can be characterized in a way that is politically palatable to all. Namely, if healthcare and entitlement programs need to be reformed such that they are rendered more efficacious while also keeping the private sector appropriately stimulated why not do so in a way that enhances the potential success of pharmaceutical R&D investments which in turn will improve public health?