

1st Place Winner! Registries for ALL: Reg4ALL

Washington, United States Washington, United States



Sharon Terry



Year Founded:

1986

Organization type:

nonprofit/ngo/citizen sector

Project Stage:

Start-Up

Budget:

\$1 million - \$5 million

Website:

<http://www.geneticalliance.org/>

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Project Summary

Elevator Pitch

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

Reg4All: The registry for all people, all diseases, all health.

The world's first participant-controlled, cross-disease health data registry. Because the haystack is made of needles.

Giving participants control, accelerating research, allowing support and trials to flow to the people.

About Project

Problem: What problem is this project trying to address?

People are looking for needles in the haystack, but the haystack is made of needles! We are missing the health research world's greatest assets: people and their health data, unified across all health and disease. People's (patients') health information must become easy to assemble, and must be done cross-disease and with the participants in control of what they share. Only then will we create the next breakthroughs in research.

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

The world's first ever participant-controlled, cross-disease registry for health and disease data.

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 are helping fuel the movement toward individuals, families, and communities reclaiming control of their health. We invite them to control the registry that contains their health data. Respecting each participant's sharing/privacy desires, we help researchers engage with people and their data: to generate research hypotheses, discover research cohorts, enroll studies/trials, and achieve breakthroughs more quickly than before.

Impact: What is the impact of the work to date? Also describe the projected future impact for the coming years.

- Thousands of users - Unlocking cooperation across ecosystem - First clinical trial ready preparing to use system - First data-based study ready to use system - Renewed hope from participant communities - Great enthusiasm from the research community

Sustainability

Financial Sustainability Plan: What is this solution's plan to ensure financial sustainability?

2013: Tens of thousands of consumer participants. Tens of studies. 2014: Hundreds of thousands of consumer participants. Hundreds of studies. 2015/2016: Millions of consumer participants. Thousands of studies.

Marketplace: Who else is addressing the problem outlined here? How does the proposed project differ from these approaches?

So many narrow or incomplete registries in the world. Some of those organizations may feel threatened by how Reg4All puts control in the hands of participants. With so many registries out there, we see some competition for the attention of consumers and researchers. But our marketing/attraction strategies will be quite different.

Team

Founding Story

My children were diagnosed with a genetic condition in 1994 and there was no treatment. We discovered there was no system for creating treatments. The aha came when I realized that while researchers were trying to find needles in haystacks, the haystack is made of needles - all citizens are able and willing if they are given the right tools - data sharing and access privacy preference tools.

Organization Name

Genetic Alliance

About You

About You

First Name

Sharon

Last Name

Terry

Twitter URL

<https://twitter.com/geneticalliance>

Facebook URL

<https://www.facebook.com/groups/15453400385/?fref=ts>

The information you provide here will be used to fill in any parts of your profile that have been left blank, such as interests, organization information, and website. No contact information will be made public. Please uncheck here if you do not want this to happen..

Innovation

Explain what the "innovation" is about, e.g., is it the idea and/or the model you use to accomplish the idea, or your understanding of the target population, etc.?

It is time for individuals to reclaim their health, like they claim every other aspect of their lives. The time for paternalism is over. It is time for individuals, families and communities to drive research—to decide who will use their health information and why. To be drivers of research. Then incentives will align. Researchers strive for promotions and funding, industry strives for blockbusters and profit, and even advocacy organizations often strive to sustain their organization. Reg4All was created with the radical idea that patients and researchers should be able to join an online network that would link the two together in the spirit of sharing information for the greater good. Patients gain access to potentially life saving clinical trials, researchers gain access to a centralized database of participants, and data will be freely shared (respecting each participant's custom sharing/privacy settings, of course!) in BOTH directions.

This idea changes the way people view their health, pushes researchers to a 2-way relationship with patients, and transforms a broken system that does not serve enough of the population.

Describe how your innovation model is distinct from any other organization in your field?

Disease advocacy organizations have attempted registries. But lacking committed researchers, often do not meet their data usage goals, and are hard to sustain financially. Commercial orgs also attempt registries, but find it difficult to sustain an environment of trust. And both advocacy and research communities too often take a single-disease approach.

Reg4All is cross-disease. It is participant centric, with trust as a founding principle. And it is designed for the widest proliferation, helping create and sustain new relationships between participants and researchers.

What type of operating environment and internal organizational factors make your innovation successful?

We operate on a 10+ year long foundation of openness, systems thinking, and respect of persons. We are a non-profit org that works like a lean startup. We surround ourselves with helpful voices. For example, we convened the ethics team for this project at its founding, making participant-centric governance a founding principle rather than just tacking on ethical oversight at the end.

We apply to health habits we've learned from the networked world. Less like traditional health research, more like facebook and twitter.

How do you make sure you constantly innovate in light of (potential) external challenges, or your growth plan?

Embracing Eric Ries' Lean Startup philosophies (Eric is a friend of one of our founders), we progress through product experiments. We see what works and we grow it. We see what doesn't work, and we adapt. We weekly (and sometimes daily) learn from our metrics and our qualitative feedback.

Think, Make, Check. Repeat. Innovation is a way of life, not a project.

Organization Country

, DC, Washington

Business Model

The systemic challenge you are trying to overcome (select one)

Realign the incentives in the public healthcare system in mature markets, or

Health area (target market) where the need is [select only one]

Care for rare diseases

Categories along the health continuum you are covering [select all that apply]

Prevention, Detection, Intervention, Follow-up, Long-term care, Social integration.

Stage that best applies to your solution [select only one]

Start-up and growth (pilot is successful and starting to expand)

Core strategies of your business model [select all that apply]

Approaches to behavioral change at the individual level, Patient-centered design, Redesign of the public healthcare system for more efficiency (in terms of processes, structure etc.), New/redefined roles for healthcare service provision, New approaches to distribution of health products and services, Unconventional partnerships (between traditional healthcare players and players outside healthcare), New financing strategies for health.

If other, specify here:

Most relevant tools you are using to implement the strategies outlined above [select only two]

Technology, New skills, Education/training, Community financing.

If other, specify here:

What is your value proposition?

For consumers: add your piece to the health puzzle and let support and research come to you.

For researchers: a high-engagement source for growing research cohorts

For disease advocacy orgs: create deep, lasting connections with your constituency and accelerate research breakthroughs

Who is your customer(s)?

- Consumers
- Researchers/Pharma Cos
- Disease Advocacy Organizaions

What approaches to you use to reach your customers?

- PR
- Links from partners
- Viral loops
- SEO
- SEM
- Events

What are your primary activities?

- Developing systems and user experiences
- Operating databases
- Exercising ethical governance
- Attracting consumers & researchers

What other challenges - individual, organizational, or environmental – are you currently facing or might hinder future success of your business, and how do you plan to overcome those?

Genetic Alliance does not have very much experience running consumer-facing web products, and doing good branding and marketing. This is why we brought in an Entrepreneur-in-Residence who has deep expertise in these areas.

We also need more cash investment during the start-up phase on our way to reaching financial sustainability.

Briefly describe your growth strategy going forward

CONSUMER SIDE: start with our core audience in rare disease. Use viral loops attract many more. Event marketing, SEO, SEM.

RESEARCHER SIDE: start with trials most desperate to enroll. Letters to researchers/medical centers. Event marketing. SEO, SEM.

What dimensions for growth are you currently targeting for your innovation [select all that apply]

New customer group(s), New regions(s), New market(s)/country(ies).

What makes your business "ready" for growth?

We have proven with a pilot that our approach works. We are receiving high levels of interest from all quarters. We have a proven, collaborative team executing. We are using lean startup techniques and will execute micro- or macro-pivots as we grow.

What are your key growth objectives?

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Organization's Country of Operation

, DC, Washington

Social Impact**What methods for quantification of social impact are you applying (if at all)?**

We have created a whole second 'product' to watch, mine, and learn from online and usage metrics (including visitors to site, conversion rate to account users, # abandoned accounts, engagement on site per visit, source of visitors, success of marketing campaigns, successful research searches, etc.).

We are in the process of building other metrics to measure more upstream impact such as clinical trials enrolled and at what speed, research questions formulated by individuals and communities and so on.

Where possible, we are thoroughly metrics-oriented.

In addition, we are commissioning longitudinal studies about use of Reg4All.

And we are seeking ways to quantify impact on the larger ecosystem.

Could your solution work in other geographies or regions? If so, where?

It is designed from the ground up to be global in reach and in service. Health and disease know no national boundaries. We are in discussions for pilot projects in India and China. This solution is particularly pertinent to areas of the globe which are currently being exploited in clinical trials because they are in less regulated countries. This will also leap frog problems we have experienced in more developed countries with a sense of powerlessness and the belief that they are channels that will work to solve that engagement. In less developed countries, individuals have some advantage in that they are not already in rigid structures that have failed in the developed nations. However, they will need simpler access, for example through text based products.

What is your projected impact over the next 1-3 years?

In the next 1-3 years we will see a greater number of individuals in clinical trials. We will see those trials enroll faster, and less trials close because of 'low enrollment'. We will see more diverse clinical trials - they will not just be the healthiest quartile of white men, they will include minorities and other underserved communities. We will also see more individuals and communities understand that they can reclaim their health. They can drive the clinical questions in trials that they believe will benefit them most.

Ultimately we will see faster drug and other therapy development, decreasing the 17 year, 90% failure rate for a one billion dollar price tag. Any improvement will save enormous amounts of money.

Sustainability**Elaborate on your current financing strategy**

We started with a grant from Sanofi. We added to that some in-house budget to get the pilot completed. In addition, development partners are donating some work.

Next, we simultaneously a) seek additional capital donations to fuel rapid growth ahead of sustaining revenue and b) begin to grow recurring revenue which will eventually sustain the whole project. Our strategy is to price access to data at price points vastly below current market rate. We are looking to iTunes and app store models - volume over high prices. At the present time, a pharmaceutical company might pay between \$5,000 and \$40,000 to accrue one individual into a clinical trial. We hope to make that price point less than \$10 per person, or even better, a sustaining subscription model like Pandora or LinkedIn.

In addition, we are offering a Kickstarter type model for companies who seek individuals in specific disease areas.

We offer tiered pricing for sponsorship for the 13,000 pages in Disease InfoSearch, for links on those pages, and for the 13,000 associated surveys in Reg4All.

And finally, we will drive some pilot programs for companies or academic institutions in specific disease areas for costs well below their current ones.

Share of revenue generation in total income of organization (in percent)

80%

Direct sales to patients or other beneficiaries (in percent)

60%

Of the possible sources of these sales listed below, check all that apply to your current strategy

Private businesses, Other beneficiaries.

Licensing fees, e.g., for technology/franchise model (in percent)

20%

Of the possible sources of these licensing opportunities listed below, check all that apply to your current strategy

Foundations, NGOs, Private businesses, National government.

Service contract with organizations, e.g., government, NGOs (in percent)

20%

Of the possible sources of the service contracts listed below, check all that apply to your current strategy

Foundations, NGOs, Private businesses, National government.

Explain your revenue generation strategy in more detail

We earn money through:

- Sponsor ad placement
- Registry services for disease groups
- Subscription fees to researchers

Share of philanthropy in total income of organization (in percent)

20%

Philanthropy strategies you are using

Diversified strategy.

Explain your philanthropic approach in more detail

Our philanthropic approach has three pathways:

- 1) We have received unrestricted grants from the family foundations of successful professionals in our field
- 2) We have applied for and received small grants from public foundations
- 3) We have competed for prizes in contests such as this and received them on occasion.

Expand on your selections; explain how you will sustain funding over the next 1-3 years.

- We will create focused success early on, then market opportunities based on those audience-specific success stories.
- We will grow our revenue channels through combination of great web based interfaces for low-touch revenue, and a small, talented sales/bizdev team for higher-touch opportunities.
- We will constantly watch for new or refined revenue opportunities to seize.

Years in Operation

Operating for more than 5 years

Has the organization received awards or honors? Please tell us about them

2007:

Sharon Terry won 1st Annual Patient Service Award from UNC Institute for Pharmacogenomics and Individualized Therapy

2009:

Sharon Terry is elected Ashoka Fellow for life.

Genetic Alliance received 2009 Research!America Award.

Genetic Alliance is named in 2009 Washingtonian's Best Places to Work list.

2011:

Sharon Terry is elected to the Institute of Medicine's Board.

Sharon Terry received 2011 Clinical Research Forum and Foundation's Annual Award for Leadership in Public Advocacy.

2012:

Sharon Terry received 2012 FORCE Spirit of Empowerment award

2013:

Sharon Terry was recognized by FDA as one of 30 rare disease heroes

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