## Project PCOS

United States  
Ashley Tabeling

### Project Summary

**Elevator Pitch**

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

By improving access to online information, resources, support and services. Project PCOS will provide links to the full range of patient and healthcare services for the consumer and provider. Through Education and partnership with the medical community, patients and organizations, Project PCOS will be able to collaborate in providing easy integration of information, in support of users’ needs.

Project PCOS wants to do more to exploit the educational potential of online technologies. Therefore, Project PCOS will do all we can to accelerate the move to the next generation of e-learning activities and resources within the health communities.

We need better digital resources to be more widely available and more flexible learning packages that healthcare providers can adapt to their patients’ needs. We must support innovation in the market by improving our knowledge of where e-learning works and we must keep information and resources moving, to take advantage of new methods in all areas, and to keep demanding a better response from the technology with utilize.

By engaging technology, Project PCOS will be able to provide an immediate response to the needs of patients and the healthcare industry through a comprehensive set of online resources and will increase awareness of this syndrome, its symptoms and the risks associated with PCOS.

Additionally, by effectively promoting and implementing PCOS research and education, the condition will be more recognizable among various medical disciplines. This will allow for earlier detection and better patient care for the PCOS Patient.

Educational materials and programs will also allow us to empower women and girls to take control of their health and live healthier lives with PCOS, while researchers continue to identify the causes of PCOS and ultimately find a cure or more effective treatments to control the syndrome.

### File attachments:

- [risk_poster.pdf](#)
- [pcospamphlet.pdf](#)
- [quick_guide.pdf](#)
- [disspellingmyths.pdf](#)
- [costs_guide.pdf](#)

### About You

**Location**

- Project Street Address
- Project City
- Project Province/State
- Project Postal/Zip Code
- Project Country

**Your idea**

**Focus of activity**

Advocacy

**Year the initiative began (yyyy)**

2006

**Positioning of your initiative on the mosaic diagram**

Which of these barriers is the primary focus of your work?

Health care not consumer friendly

Which of the principles is the primary focus of your work?

Democratize access

If you believe some other barrier or principle should be included in the mosaic, please describe it and how it would affect the
Innovation

Define the innovation

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Context for Disruption:

The complexity of PCOS (Polycystic Ovary Syndrome), coupled with poorly designed healthcare delivery systems, has made it difficult for clinicians to provide high-quality care for patients with this syndrome on a consistent basis and has resulted in a healthcare system building unnecessary costs, inappropriate practice variation, and suboptimal care.

Often unrecognized PCOS (Polycystic Ovary Syndrome) can cause many physical and emotional manifestations and for the up to 15% of women and girls with Polycystic Ovary Syndrome Worldwide, it is estimated less than half know what it is or that they have it. Therefore, Project PCOS is charged with identifying strategies for achieving substantial improvement in the quality of health care and education for all patients living with the syndrome.

Project PCOS must keep up with the current demands for information by supporting an organizational structure and programs capable of handling and satisfying the mass inquiries received and the need for reliable resources for consumers.

Project PCOS has been responding to these inadequacies with an emphasis on PCOS related research and the needs of educational instruction, clinical teaching, and delivery of education via distance learning, support services and use of educational technology.

Although there have been various resources available with regards to PCOS and PCOS support, none of these resources have been able to bridge the gaps between patients and healthcare providers, often leaving the patient at a loss trying to comprehend the mountains of data about the syndrome, without the tools to implement this information in to their healthcare.

By using technology, support and volunteerism, Project PCOS will be able to provide comprehensive and accessible resources about PCOS for all who seek it and will lower the cost of healthcare for providers, as an initial diagnosis of PCOS and treatment options will save millions of dollars in the treatment of this syndrome.

Delivery Model

Project PCOS will use the expertise and resources of its experts and its partners to improve the health status and well-being of all PCOS patients. In doing so Project PCOS will provide access to educational resources and information for patients and professionals at both online and offline educational events, identify gaps in PCOS care education, develop and implement a School Education Program and form collaborative relationships with educational providers and professional groups.

Project PCOS continues to increase its effectiveness and reach through strategic online and offline partnerships with websites, health and patient advocate organizations, the health industry, patient advocacy groups and PCOS Community forums, websites and resources. Additionally, we attend and provide educational seminars, industry conferences and participate in outreach programs to improve health services and community outreach.

Project PCOS has monitored a major increase in traffic to ProjectPCOS.org and inquiries from patients, professionals and the media. We are able to review this data on a consistent basis through analytics, monthly website reports and database systems that allow us to track all internal and external communications and activities.

Project PCOS also reviews the ROI of all projects and partnerships through measurable means and reports to the executive board of the organization for review and revision

Through use of online technologies as a key delivery channel, the goals of this initiative can be far reaching. Blogs, forums, social platforms, websites and directories reach millions of people everyday

This information is intended for use by patients, healthcare providers and practitioners, the media and the public at large and as such is tailored to be accessible and understandable for all visitors to the website.

Key Operational Partnerships

Project PCOS has currently established and continues to establish partnerships with organizations, websites and healthcare providers who share our mission and are able to help us obtain our goals through open communication, shared resources and collaboration.
Project PCOS has partnered with organizations, websites and advocates including but not limited to: The American Electrolysis Association, RESOLVE, The Hormone Foundation, Aphrodite Women's Health, Center for Applied Reproductive Sciences, Virginia Commonwealth University PCOS Research, University of Chicago PCOS Center, The Endocrine Nurses Society and Livin La Vida Low Carb to ensure PCOS patients are provided with the most up-to-date and reliable resources to manage their symptoms and overall health.

These organizations help provide and collaborate on PCOS educational and patient resources to allow for more communication between patients and professionals, provide education for the various symptoms of PCOS such as acne, infertility, gynecological care, hair removal options and natural options and open communication with their constituents to ensure Project PCOS has a voice within their communities and within public forums.

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**Impact**

**Financial Model**

Project PCOS has been established through private funding and anticipates it will continue to operate through personal contributions, donations, sponsors, advertisers and supporters through the remainder of 2007.

Project PCOS is in the process of establishing an operational budget to be put in place for 2008 and continuing thereafter. This model will be consistent with most non-profit operational practices.

Future support shall be requested and obtained through grants, sponsorship, planned giving, partnerships, donations, affiliates and Project PCOS products and services.

Funding received from these practices will be applied towards operational costs including staffing, PR and marketing, development, educational resources and community outreach.

At least 25% of the earned income from Project PCOS is anticipated to be supported by products and services offered through the Project PCOS Organization and website.

The remainder of the funding shall be earned from the aforementioned sources.

A projected annual budget and operational breakdown can be furnished upon request.

**What is your annual operating budget?**

75%

**What are your current sources of revenue? (please list any sources that are foundation grants)**

Private funding, advertising and donations are the primary source of funding at this time.

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**Effectiveness**

Since Project PCOS unveiled its website and campaign in February of 2007, we have measured a mass influx of pageviews, visitors and requests for information about PCOS. While the scope of our outreach is hard to completely define, as the outreach is so vast, we imagine to date our services have benefited consumers and health care providers with numbers in the thousands.

Project PCOS is now working with a collaboration of healthcare providers, community advocates and medical professionals to define criteria for proper diagnosis and treatment of Polycystic Ovary Syndrome and Project PCOS is in the process of creating advisory and medical boards to ensure patients and providers have access to resources, tools and educational materials that are consistent with current beliefs and standards of both medical and business communities.

Additionally, Project PCOS is participating as speakers at conferences that influence the cost and effectiveness of women's health care and target the healthcare industry to help facilitate change. With the proper foundation and funding in place, Project PCOS envisions we will reach millions of consumers and providers by the end of 2008.

**Which element of the program proved itself most effective?**

Community Forums, which provide peer support, information and networking for community members and allow community members to directly communicate with experts who will answer their questions regarding PCOS and PCOS related symptoms and risks.

Patient Communication has always played a key role in the PCOS Community and Project PCOS is ensuring this continues to occur in a format that is accessible, secure and comfortable for our community members.

Community Forums remain the most effective way for patients to communicate and learn about PCOS in a way that is friendly, understandable and relevant to their needs.

Therefore Community forums have and will remain at the pinnacle of PCOS information and awareness, making it our most effective means of communication and outreach amongst the community.

**Number of clients in the last year?**

As Project PCOS serves the entire community with free services, we do not have or solicit clients. We do however, provided information and services for thousands of patients and healthcare providers.

**What is the potential demand?**

The demand is almost immeasurable, as PCOS affects up to 15% of the female population but, as previously stated, we estimate less than half know what it is or that they have it, the numbers are most likely much greater.

As more women and girls become aware of this syndrome and are diagnosed, the need for reliable information and resources will only be compounded, which makes the services and information that Project PCOS provides vital to the overall care of the PCOS Patient and
**Scaling up Strategy**

By effectively promoting and implementing PCOS research and education, the condition will be more recognizable among various medical disciplines. This will allow for earlier detection and better patient care of the PCOS Patient.

Educational materials and programs will also allow us to empower women and girls to take control of their health and live healthier lives with PCOS, while researchers continue to identify the causes of PCOS and ultimately find a cure or more effective treatments to control the syndrome.

Project PCOS aims to develop an evaluation framework to:

- underpin the best practice of PCOS care education.
- Identify research studies that are being conducted.
- Provide assistance in study recruitment.
- Provide vehicles for promotion of research studies.
- Establish partnerships with individuals, professionals and organizations with an interest in fostering PCOS research with Project PCOS
- Provide opportunities for researches to network and disseminate findings.
- Host online chats with professionals and guests
- Provide downloadable educational documents.
- Provide physician moderated message boards.
- Make information available through newsletters, website and e-mail.
- Actively support issues and practices that enhance the education and circumstances of women and girls with PCOS.
- Promote public education and the important role it plays.
- Develop an ongoing and broadly based education and advocacy program targeted to local, state, and national government leaders and the media.
- Work with liaisons and professional groups to enhance Project PCOS's role and visibility among professional communities.
- Provide online and offline education seminars for patients and providers.
- Establish a strong staff and structure to meet with public demands.

By focusing on these priorities Project PCOS will foster improved education, research funding, and knowledge in the diagnosis, treatment, and prevention of PCOS.

**Stage of the initiative:**

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**Expansion plan:**

Project PCOS will establish processes and positive outcomes that will result in physicians and patients becoming integral, engaged partners in PCOS awareness and treatment with Project PCOS being able to supply a full compliment of educational resources, support and advocacy through the use of online technology.

Women and girls with PCOS, their families and supporters will have excellent support and advocacy resources available to them, including but not limited to web services, online discussion forums, online chats, periodical e-newsletters, stock publications, conferences and symposia and local support.

Through establishing funding and staff through 2007, as well as completing operational policies and strategic plans, Project PCOS will be the leading provider of PCOS education, information and support for patients and providers.

**Origin of the Initiative**

Project PCOS, began as a truly virtual organization.

In late 2006, a group of PCOS Awareness Advocates and patients were all responding to the same needs of the community through communicating via various online support groups. The group began e-mailing each other to discuss ways in which they could create a comprehensive and cohesive source of information, awareness and support for PCOS Patients. Ashley Tabeling, an active member of this budding ideal, quickly began implementing these ideas to create a unique and interactive site for and about PCOS.

Almost immediately, the list of people participating in this endeavor began to grow and within a short period of time, over 1000 individuals signed up for the forums, website and information about PCOS began popping up and information that had been difficult to obtain and comprehend by patients was now being shared freely online.

**Sustainability**

**What are your two main challenges to finance the growth of your initiative**

PCOS is still often misdiagnosed and/or undiagnosed, as many medical professionals are often unaware of PCOS or the impact of PCOS Symptoms. Therefore policies, funding and recognition will continue to be a challenge until many disciplines throughout the healthcare industry recognize PCOS as a significant health concern that puts patients at risk for major health conditions including stroke, heart disease, diabetes and cancer.

Additionally, PCOS which affects up to 15% of the female population, is listed as a rare disorder in national registries. Therefore, until perceptions are changed and legislative action is taken, many potential partners, sponsors and funders will be difficult to solicit.

**How did you hear about this contest and what is your main incentive to participate?**

We learned of this competition searching for grant matches. We were encouraged to participate as we believe there are many roadblocks within the
healthcare system which prevent patients from receiving the quality of care they deserve. PCOS is the perfect model for showing the need for change.

The Story

Do you have an annual financial statement?

As Project PCOS came to existence in February of 2007 and is in the process of becoming a non-profit, we do not currently have financial statements. We do however have documentation of our application to become a 501c3, our incorporation, proposed budgets and account records which can be furnished upon request.

Do you currently have an annual financial statement that tracks profit/loss?

Project PCOS will require $206,000.00 for the operational costs of the organization, its initiatives and programs for year one. Thereafter, we anticipate yearly costs will increase about approximately $75,000.00 per year to be capped at $500,000.00 per year by the five year mark.

Costs at start-up will include but are not limited to general operating costs including administration, accounting and legal fees, PR, stock of educational materials for patients, medical professionals and healthcare facilities, travel, development and maintenance of website and support services.

Over the following years initiatives will include educational seminars and conferences for patients and professionals, advocacy and awareness campaigns, addition of more online and offline services, and funding development.

Please describe the amount (and/or type) of funding you need to implement your initiative, at year 1 and at year 5.

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