



# BRIDGING THE NETWORK GAP

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**A public relations campaign.**

From the students of Professor Mitrook's Advanced Public Relations course.  
University of South Florida, Spring 2011

Strategic plan for improving the awareness and effectiveness of the Rare Disease Clinical Research Network (RDCRN).



# FROM THE PR TEAM

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The University of South Florida's Advanced Public Relations class would like to offer a look into our campaign to improve the awareness and effectiveness of the Rare Disease Clinical Research Network (RDCRN).

The strategies in this campaign have been developed to meet four primary goals:

1. Improve the quality of contact with consortia members
2. Standardize frequency of contact with consortia members
3. Increase the number of medical professionals who know about and support the RDCRN
4. Improve the usability and appearance of the RDCRN website

Our research has shown that many registry members do not understand what the RDCRN does, and many physicians are not as familiar with the registry as they should be. The registrants do not understand what to do after they register, and are often left in the dark when no follow-up contact is made with them after they join. In addition, the RDCRN website makes the registration process itself stressful and confusing, which may have caused a number of potential registry members to give up on joining.

With the implementation of this campaign, the public relations team believes that the RDCRN will increase enrollment, improve retention of current members and build a strong network in the medical community to support the registry and to drive recruitment.

We hope that the RDCRN staff will take the time to read over the campaign details enclosed and follow as many of the public relations team's suggestions as possible, in order to see the best results.

Sincerely,

Dr. Michael Mitrook's Advanced Public Relations students



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# BACKGROUND

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## Executive Summary

The Rare Disease Clinical Research Network (RDCRN) is a unique registry that is still fairly new in the aspect of medical advancements. With no direct competing organizations, this not-for-profit organization has the potential to excel in the development of research and cures for rare diseases.

Created in 2004, the registry has accomplished what it could under strict guidelines due to its past grant cycle. Promotion efforts for the RDCRN in the past have been minimal, creating a great need and opportunity for multi-method promotion. Currently in their second grant cycle, RDCRN is now allowed more flexibility in their functionality. In hopes to grow the registry and receive more grants, the network is focusing on ways to advance their communication efforts with current and potential patients.

One important factor of the network is the funding it receives. This not-for-profit organization receives its funding through federal grants, and the number of patients within the consortium determines how the funds are distributed. This creates an internal competition because federal funding is more likely to fund those consortia that will impact the greatest number of patients, rather than the more rare diseases that only have a few registered patients. The importance of funding for the network ties in with the importance of promotion for this registry. This is because the greater the acknowledgement of the registry, the greater the chances for discovering a larger number of patients suffering from the rare diseases.

Currently, about 6,000 people are registered for the RDCRN, spreading the patient base worldwide. Current membership was gained solely by word of mouth, giving hope to the registry for a broader reach with a greater emphasis on communications.

## Purpose & Objectives

### Purpose

The Rare Disease Clinical Research Network (RDCRN) is made up of 19 distinctive consortia that are working to improve:

- Availability of rare disease information
- Treatment
- Clinical studies
- General awareness for both patients and the medical community

With improvements being made within the network, the RDCRN is seeking to expand its registrant base and provide better service to current members. The RDCRN has the opportunity to provide a greater volume of more valuable information to registrants, and is searching for ways to improve member retention by proving its worth to current members. Registrants will now be presented with better study-specific information given by the RDCRN, and the network recently





made alternate enrollment options available, allowing consented users to be contacted by study staff for screening.

RDCRN is focused on providing up-to-date information for patients along with assisting in connecting patients with:

- Advocacy groups
- Expert doctors
- Clinical trial opportunities

### **Objectives**

The registry has the potential for major growth and expansion. To achieve these goals, the RDCRN will focus on the following objectives:

- Enhance and expand communications
- Grow registry enrollment
- Create value for members
- Earn greater NIH/Sponsor funds

Currently the RDCRN works with NIH'S Office of Rare Disease Research. The registry is led by a steering committee consisting of 19 representatives, leaders from the RDCRN and advocacy group representatives. So far, word of mouth has been the primary method for expanding the registry and reaching its long-term goals. The RDCRN is currently creating a registry kit to help drive membership. Along with the registry kit, the registry has advocacy groups that help direct potential registry members to the website. Since past tactics for improvement and expansion have been so limited, the registry can expect to see major improvements through the strategic implementation of communications tactics.

## **Composition**

### **Governance Structure**

Jeffrey Krischer, Ph.D. is the director and principal investigator of the Rare Diseases Clinical Research Network (RDCRN). Rachel Richesson, Ph.D. is the co-investigator. Under them are:

- 16 clinical research administrators
- 14 developers
- 15 faculty members
- Five information technology staff
- Six research associates
- Three quality assurance employees
- Multiple administrative and support staff

In total, there are about 90 people who are involved within the entire organization. Approximately 20 of these employees, including project managers who work with the consortia, are involved with rare disease grant studies in the state of Florida.

### **Client Assistance**

In order to plan and meet its goals, the RDCRN works with the National Institute of Health (NIH) and the Office of Rare Disease Research. In addition, the RDCRN has a steering committee and multiple subcommittees to assist the RDCRN in reaching its goals.

## **Relevant Publics**

Relevant publics of the Rare Clinical Diseases Research Network include, but are not limited to: healthcare professionals, educators, the public, those who suffer from rare diseases, as well as their friends and family. With the registry being specifically created to inform patients of clinical studies, the RDCRN sees it as essential to focus on those individuals who are directly dealing with a rare disease, as well as advocacy groups. The contact registry is not limited to a particular demographic, but rather encourages patients from all over the world to join.

## **Funding**

Funding is essential to the productivity and development of the Rare Disease Clinical

Research Network. The majority of the registry's grants are received through the National Institute of Health, an agency administered by the U.S Department of Health and Services, which offers the largest source of funding for medical research in the world

The RDCRN has a U54 grant; a collaborative agreement given to research institutions to foster communication, innovation and high-quality research. In 2009, the RDCRN received a \$17 million grant from NIH that will be awarded over a period of five years. The new funding is due to the institution expanding into phase II and now research will explore the natural history, epidemiology, diagnosis and treatment of more than 95 rare diseases.

Dr. Jeffrey Krischer, professor and director of the University of South Florida's Pediatrics epidemiology, is a major contributor and has implemented scientific findings that have led to clinical trials being funded through NIH. Krischer also serves as the Principal Investigator of the RDCRN Data and Technology Coordinating Center.

Through Krischer's efforts, the RDCRN received over \$9 million in 2010. That funding will help RDCRN provide secure, coordinated data management services for collection, storage and analysis of diverse data types from multiple diseases and geographically disparate locations.

Ultimately, the funding and grants that RDCRN receives helps the institution reach its goals. Based on the RDCRN biennial 2006-2009 report, a minimum of \$18 million is needed to execute yearly operations of research studies. However, a research expansion or phase requires a significant amount of money that may range over \$100 million.

## Competitive Frame

The Rare Diseases Clinical Research Network is essentially a unique client with no direct competing organizations. Being a not-for-profit clinical organization, its mission is to provide its publics with beneficial services that aid in the treatment of rare diseases.

While this means there is no direct competition, as there might be with a for-profit organization seeking to boost sales, the RDCRN still faces challenges in which publics may resist association or involvement with the registry network.

Each of the 19 consortia associated with the RDCRN is very diverse in terms of dynamics and size, and each has different goals. While the client is looking for an overall strategic communications plan, it's still important to realize the individuality of each consortium. Although there may be great strength in numbers, the registry's size and diversity present challenges when attempting to address the varied needs of the consortia.

Additionally, the RDCRN is federally funded, and each grant cycle presents changes in funding. The participating consortia compete for funding during each cycle, and the competition can be fierce. While some consortia may receive increased funding, some may be completely taken off federal funding. Funding is generally based on studies and publications presented by each consortium, as well as overall activity and the number of registered patients.

The number of patients within a consortium reflects an internal competition. One consortium, simply because of the nature of the disease, will not have as many members as another consortium whose disease is more widely known. The challenge presented here is communicating the value and importance of each consortium, regardless of the number of registrants. Never the less, federal funding is likely to favor those consortia that will impact the greatest number of people.







# CURRENT SITUATION

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This section will explain the current situation of the Rare Diseases Clinical Research Network, while highlighting these important points:

- The challenge of revamping the website
- The opportunity to do more and be more for its publics
- The opportunity to branch out from founder to take charge of media relations and coverage

In the opinion of the public relations team, the RDCRN is not reaching its full potential primarily because of the current state of its website. The bulk of the RDCRN's interactions and operations with its rare disease patients are online, but its current website is cluttered and lacks the information needed to make it a helpful resource and tool for rare disease patients and patient advocates. In modifying the website, it will be important to keep in mind the federal funding received by the organization and to abide by rules set for federally funded websites, such as the Americans with Disabilities Act of 1990, which requires that all federally funded websites be 508 Compliant.

The RDCRN also has a special public that it reaches and it has the opportunity to do more for its rare disease patients than simply providing information. This is a key opportunity that our public relations campaign will address, transforming the organization into one that provides support and opportunities for discussion while still informing its publics.

Lastly, media relations, publicity and media outreach for the RDCRN thus far has been pioneered by the National Institutes of Health. While a potential difficulty, this 'clean slate' situation puts the RDCRN in a great position to branch out from NIH and begin creating and using its own media materials and programs.

Through its public relations efforts, the RDCRN wants to establish itself as a valuable source of information and resources for its registrants, potential registrants and the medical community in general. Improved marketing materials, website layout and communications strategies will assist the network in achieving these goals.

## Development

The Rare Diseases Clinical Research Network was founded by the National Institutes of Health on November 3, 2003. To be coordinated primarily by two NIH components (the Office of Rare Diseases and the National Center for Research Resources), the RDCRN was created in response to the Rare Disease Act of 2002, which directed NIH to support "regional centers of excellence for clinical research into, training in, and demonstration of diagnostic, prevention, control, and treatment methods for rare diseases."

The RDCRN began with seven Rare Diseases Clinical Research Centers, located in Houston, Texas; Boston, Mass.; Cincinnati, Ohio; Washington, D.C.; Cleveland, Ohio; Rochester, NY; and New York, NY; and a Data and Technology Coordinating Center (renamed Data Management and Coordinating Center), located in Tampa, Fla.

On May 5, 2006, NIH announced the RDCRN's first clinical studies to investigate a variety of rare diseases. The RDCRN received five-year funding awards totaling \$71 million, enabling the central DMCC and 10 research consortia to investigate a variety of diseases including, but not limited to: Angelman, Rett, Prader-Willi syndromes; myelodysplastic syndrome and other bone marrow failure conditions; lymphangioliomyomatosis (LAM), rare genetic disorders of the airways, and other rare lung diseases; episodic ataxia, Andersen-Tawil syndrome, and nondystrophic myotonias; several vasculitides; urea cycle disorders; antiphospholipid syndrome and other rare thrombotic diseases; rare pediatric liver diseases; and rare genetic steroid defects.

On October 5, 2009, NIH announced the implementation of a second phase of the RDCRN in which 19 consortia and the DMCC were awarded five-year funding of just over \$117 million to explore the natural history, epidemiology, diagnosis, and treatment of more than 95 rare diseases.

The RDCRN is currently in the second year of its second grant cycle, during which it has been funded to work with 14 new studies and consortia. Consortia vie for participation funds in each grant cycle and the process is highly competitive. The amount of funding received is determined by: the number of studies and publications completed, overall activity, and number of people registered in these studies.

## Current Position

The Rare Disease Clinical Research Network has several communities on which it focuses its communications efforts. Since the Data Management and Coordinating Center (DMCC) is located in Tampa, the Bay area makes up one of its focus communities. However, there is little indication of a relationship between RDCRN and the Tampa Bay area, which may be due to a lack of awareness about the network. There appears to be little to no direct community involvement or communication with Tampa Bay through media or other channels of communication. The community's lack of awareness creates a disconnect between the RDCRN's DMCC and its Tampa Bay home.

The Rare Disease Registry makes up another, albeit digital, community for the organization. Since the registry and its consortia make up an internal public, there is a much stronger relationship between the RDCRN and the registry. The network connects with registry members through emails and newsletters, informing members about clinical trial opportunities and new developments. Though there was a recent enhancement that allows patients to contact researchers, the current method generally leaves little opportunity for

two-way communication, creating a one-sided relationship with the registry community.

The Coalition of Patient Advocacy Groups (CPAG) is the third major community with which the RDCRN is associated. The two groups work together to improve patient awareness and help attract members. There appears to be a moderately strong, and mutually beneficial, relationship between the network and the advocacy groups that drive patients to the registry.

## Direction

The RDCRN strives to assist in the development of cures for rare diseases by providing a means for researchers to communicate with potential clinical trial participants. However, there is a lack of direct communication between the registry, consortia, and current and potential registrants. This becomes a problem, because registry members receive little benefit from their membership without any communication. By enhancing communication efforts, the RDCRN can provide members with valuable information, resources and opportunities to participate in clinical trials. By serving its current membership well, the RDCRN will develop its members into advocates for the registry and will also drive increased enrollment by proving itself as an invaluable resource.

Currently, the RDCRN only allows U.S. residents to participate in research studies. Strategic marketing can transform the RDCRN into an international organization; however, there must be a language and translation support system. The enhancement of communications can significantly increase registry enrollment, and may also result in international funding opportunities.

## Vision

Ultimately, the RDCRN's vision can be divided into two central themes: increasing enrollment and enhancing the value of membership. Increasing enrollment in the registry is important to its survival, but the staff of the RDCRN knows that registrants are more valuable if they stay in the registry and remain involved.

The RDCRN also recognizes that a well-planned public relations campaign has the ability to enhance communications with the registry and to create added value for members. Each of the 19 consortia act independently of each other and of the RDCRN, so the intention would be to create guidelines and tools to help the consortia manage their own communications with their members. The RDCRN expects that communications efforts will enhance the benefit members receive from the registry, and will thus increase satisfaction and retention. The RDCRN could also benefit from improved communication with patient advocates, increased presence at national conferences and events, and strategic partnerships with other rare disease focused organizations. Each of these individual tactics would support the goal of increasing recruitment to the registry.

Because of the complexities of the publics and the diversity of all the consortia involved, the communications strategy will need to be carefully targeted and diverse in its tactics. The RDCRN seeks involvement and active participation from each of its member consortia, and realizes that goals will only be met if all members are kept on the same page and a part of the same communications strategy.

## Pitfalls

In today's Internet age, it is extremely important for every company, no matter how large or small, to establish a presence online. While the registry website is functional, it has a few problems, relating mainly to its composition rather than its content.

The website's homepage lacks a focal point and makes the mistake of placing far too much information on the landing page, which tends to be intimidating and overwhelming. This layout also makes it difficult to convey key messages since there is so much information and a lack of hierarchy. While it is fine to scroll to look for the information, users should not have to do this on the home page. The home page should be well edited, without much more than the company's mission, latest information and a simple navigation menu.

The domain name also raises issues, mainly because it lacks the full RDCRN name and is difficult to remember. The site navigation is bland and poorly organized, making





ing it difficult for visitors to figure out where to click to find what they need. The key to a good website is ease of use, and the public relations team believes that small changes to the organization and layout of the RDCRN website have the potential to make a huge difference for the registry.

In terms of the registry itself, the RDCRN is labeled a “network,” but is not living up to its full potential as such. While patients can join the registry to participate in research studies and receive other information, the network is capable of more. It would be possible to create a real network that allows patients to reach out to one another and share stories, providing social support they may not be able to find in their hometown. This would create an added benefit for registrants and would likely result in higher enrollment figures.

COHESIVE  
DESIGN

SIMPLE  
ACCESS

PERSONAL  
STORIES

LOCAL  
FOCUS

EASY NAVIGATION

CONSORTIA  
INTEGRATION

+ INSPIRATIONAL  
MESSAGES

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**AMAZING  
WEBSITE**





# RESEARCH REPORT

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Research for the Rare Disease Clinical Research Network was conducted using three survey methods: a multiple-choice survey for both physicians and patients, a website usability test, and a focus group of advocacy leaders. The sections below offer a summary of our findings.

## Patient Findings

- Online forms are confusing to fill out. Not in chronological order.
- Want more communication from their consortium.
- Many patients did not understand how to use the registry.
- Many believed they were automatically registered for clinical trials after they registered with the RDCRN.

## Physician Findings

- 52% of physicians surveyed were only somewhat familiar with the RDCRN's contact registry.
- Almost 30% said they were not familiar with the RDCRN's contact registry at all.
- Most physicians do not currently provide contact materials to their patients.
- Most said they would use the RDCRN's registry if familiar with it.
- Almost 70% of physicians said they would pass out brochures in the office.
- 86% of physicians also said they would promote it through word of mouth.
- Usefulness of the RDCRN is unclear to many physicians.
- Physicians feel overwhelmed with emails.

## Focus Group Findings

- Patients don't see how the RDCRN benefits them.
- Patients don't see real world application, only data.
- Researchers would like more support recruiting new members.
- Researchers would like more patient retention within the RDCRN.
- More frequent communication with each consortium is necessary.

## Usability Test Findings

- There was too much information clogged together.
- The website is disorganized.
- The registry link is difficult to find, with both participants taking nearly 2 minutes to find it.

## Statement of the Problem

The Rare Disease Clinical Research Network (RDCRN) aims to expand its rare disease registry while simultaneously strengthening its relationships with currently registered members to fulfill the ultimate goal of discovering cures for rare diseases.

### Current problems include:

- lack of communication between publics
- limited patient use of registry
- the unique challenge of connecting with people with rare diseases
- lack of two way communication
- inadequate and outdated communication and information dispersion

Through our research, we sought to discover what issues currently affect the RDCRN and what improvements can be made to:

- increase member satisfaction
- make recruitment efforts more effective
- increase website usability

Answering research questions surrounding these ideas allowed us to select communications tactics best suited for the RDCRN. Our research suggests that the RDCRN has the potential for great improvement and expansion of services.

After meeting with the RDCRN, determining its current problems and getting an idea of the network's desired outcome, we developed the following goals:

1. *Improve the quality of contact with consortia members*
2. *Standardize frequency of contact with consortia members*
3. *Increase the number of medical professionals who know about and support the RDCRN*
4. *Improve the usability and appearance of the RDCRN website*

Since the RDCRN is a non-profit organization, promotion, rather than advertising, would be more important for the network. The public relations team suggests using websites, such as [www.helpareporterout.com](http://www.helpareporterout.com), to monitor the media for potential feature story opportunities. The public relations team also suggests creating partnerships with other related organizations during events to spread the word about the registry.

The RDCRN is looking to strengthen relationships with registered members while effectively expanding the registry to a worldwide population. A broadened registry and open communication would enable the RDCRN to gather more information on rare diseases. The members will reap the benefits of these efforts, as the increased registrant pool will open doors for members to communicate with physicians, researchers and other members. Increased information acquired by the

RDCRN will generate a better understanding of rare diseases and perhaps help in finding cures.

The public relations team believes that the RDCRN has not expanded to its full potential due to lack of communication between its publics and limited medium use. The network has faced difficulty in relationship building and growth due to the small population who are affected by rare diseases. With such a limited audience, two-way communication becomes more difficult. Lacking two-way communication in this case leaves members searching to contact the RDCRN instead of the RDCRN reaching out to its audience. People with rare diseases would feel more trusting of the network and would be reassured that the RDCRN has their best interests at heart if they were being sought out by the organization. This provides reassurance that the RDCRN genuinely cares and is eager to help people with rare diseases.

The issue of inadequate and outdated communication and information dispersion is a disadvantage to both the RDCRN and its members. Improving these areas will accomplish the RDCRN's goals of enhancing communication between members, and expanding member and physician data and international recruitment. Improving communication will also assist in connecting patients with advocacy groups, expert doctors and clinical research opportunities; members will get the latest medical information faster.

## Phenomenon Observed

The RDCRN currently serves people suffering from rare diseases. However, their friends, families and community members have not been made target audiences. As a group, we have observed that the registry has a vast amount of potential to serve and educate more individuals. We also believe that the registry has the ability to reach more potential members by improving relationships with medical professionals, who are the primary

recruiters for the registry.

## **Benefit of Answers**

Answering our questions has allowed us to build a campaign to best fit what the RDCRN needs and wants to accomplish. Our campaign is built upon the foundation laid by the results of our research, and it is tailored to address the RDCRN's goals of increased enrollment. Also, it will settle any problems current members have with the RDCRN, which will improve member retention and participation. We have used our research results to analyze which communication practices have been effective for the RDCRN, which areas of communication need improvement and which tactics need to be added into the RDCRN's communication strategies.

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# PLANS, GOALS & OBJECTIVES

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The Rare Disease Clinical Research Network's main struggle is with communicating effectively with both consortia members and medical professionals. The RDCRN's website also needs improvement, as it is difficult to navigate. Due to the weak relationships between the consortia, medical professionals and the RDCRN, there are no standards set to ensure consortia members are contacted regularly with engaging and constructive information.

The RDCRN's main objective is to increase enrollment in the registry. To accomplish this, we hope to improve upon current communication efforts, as well as to make recommendations for improving the website's usability and appearance. The main objective of increasing enrollment will be measured by the number of consortia members at the start of the campaign and the end of the campaign.

The use of various research tools, including surveys, focus groups and usability tests, will help to decide the best ways to communicate with both the consortia members and medical physicians. End results will help determine the amount of contact and type of content the consortia members would like to receive, help generate marketing materials to share with physicians, and determine what is not clear on how to use the RDCRN website.

## Statement of Policy and Intent

### Problems to address:

#### 1 **Communication with consortia members**

The RDCRN's consortia have extremely varied contact with their members. Many consortia contact members less than twice per year. This lack of contact reduces the benefit of joining and staying with a consortium. The RDCRN's various consortia need a set of minimum contact standards to guide their communications.

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#### 2 **Communication with medical professionals**

Medical professionals are essential for connecting the RDCRN to potential members. Currently, the materials used to inform medical professionals about the RDCRN are outdated and lack personality. Also, strategies for reaching out to medical professionals are unclear. The public relations team would like to prepare a strategic plan for the RDCRN to network with medical professionals through marketing materials, national events and the Internet.

#### 3 **Website**

The RDCRN website is the first thing potential members encounter when attempting to join a consortia. Being the face of the RDCRN, the website should be easy to navigate and understand, and should also communicate that the RDCRN is a well-established and trustworthy organization. Currently, the website does none of these things. The landing page is cluttered, disorganized and difficult to read, which immediately frustrates visitors. Usability testing has shown the site to be so irritating and difficult to use that it could very feasibly prevent potential members from joining the RDCRN. For this reason, the public relations team considers reorganizing and restructuring the website to be a high priority within the campaign.

## Campaign Goals

This campaign is based off of four primary goals:

1. *Improve the quality of contact with consortia members*
2. *Standardize frequency of contact with consortia members*
3. *Increase the number of medical professionals who know about and support the RDCRN*
4. *Improve the usability and appearance of the RDCRN website*

The public relations team believes that the four main goals listed above will accomplish the client's objective of increasing enrollment in the RDCRN's various consortia.

## Overall Plan

### **The overall plan of the public relations team is to:**

**1** Use the survey of consortia members to create a communication plan for the various consortia. This plan will outline annual minimum contact levels and will provide sample emails to assist researchers in generating content.

**2** Use data collected from the focus group with consortia leaders and medical professionals to generate new marketing materials for the RDCRN to share with medical professionals.

**3** Rework marketing materials into a potential-member kit for physicians and patient advocates to offer to patients who might benefit from membership in the RDCRN. This kit would explain the purpose of the RDCRN and offer general information about the registry and some of its larger consortia.

**4** Create a national event listing for the next several years for the client to use for promoting the RDCRN. The client could either plan to attend the events, send representatives, send information to event coordinators to share with attendees, or even volunteer to speak at the events. Any of these options would provide increased exposure to both medical professionals and potential registry members.

**5** Put together suggestions for website improvements for the client to share with its web developers. These suggestions would be based off of observations of the public relations team and the results of two usability tests.

### **Achieving Our Goals**

The plans of the public relations team to create a set communications plan for various consortia, to create national event listings and to build a potential member kit all directly relate to the RDCRN's goals to improve the quality and frequency of contact with consortia members.

Plans to generate new marketing materials and create national event listings will increase the quality and frequency of communication with medical professionals. These plans will also increase exposure to the RDCRN and help to increase the number of medical professionals who support the RDCRN and recommend the registry to their patients.

If utilized by the RDCRN, website improvement suggestions will help to improve the usability and appearance of the website.

### **Rationale**

The plan created by the public relations team is built to achieve the goals of the RDCRN. Our recommendations are based off of a number of "best practices" we have observed and also the results of our research. The research indicates that improving information quality and contact frequency between consortia and members, increasing physician awareness about the registry through development and distribution of communicative materials and improvement of the usability of the registry's website will all contribute to the primary goal of increasing enrollment in the registry. These changes will also assist in retaining current members.

### **Overall Theme**

The overall theme of the plan is to create a greater awareness of the registry in order to increase the number of registrants. Building relationships with medical professionals will help to draw in new members for the consortia, and improving communication between the consortia and their members will encourage more active involvement of members. We believe that happier, more satisfied members will result in greater trust in the consortia and increased participation in medical trials and studies.

## Contribution to Organizational Goals

### Goals of the Organization

The client's main goal is to increase enrollment in the RDCRN's various consortia, which will allow researchers to fill clinical trials, as well as create an added value for registry members and consortia leaders. Secondary goals of the client include strengthening its relationship with current members, improving registry member satisfaction and increasing awareness of the RDCRN among medical professionals.

### Support of Organization Goals

Our public relations plan has been designed specifically around the primary and secondary goals of the RDCRN. The plan focuses on the RDCRN's goal of increasing enrollment, as well as improving communication and relationships with those currently enrolled in the program. It also involves strategies for increasing RDCRN communication and awareness throughout the medical community, which contributes to the client's primary goal of a membership increase.

### Desired Results

As a result of our public relations plan, we hope to meet the objectives constructed from our four main goals. We would like to improve the quality of the RDCRN's contact and communication with consortia members. This includes increasing the amount of information being sent to members, the frequency with which these members are being contacted and the members' awareness of other members with the same or similar rare diseases.

We would also like to see an increase in the number of physicians who know and support the RDCRN. Physicians play a crucial role in recruiting members for the consortia because they have the trust of their patients. With physician support, the reg-

istry will be able to accomplish its goals of increasing membership and contributions to distributed information.

We have hopes to also see improvement in the usability and appearance of the RDCRN's website. We suggest that the RDCRN condense information and text on pages so the information is presented more clearly and the registration process for new members becomes much simpler. Better functionality of the website can increase the number of members registering and returning for additional information and updates.

## Statement of the Objectives

### 1<sup>st</sup> Objective

The primary objective of this campaign is to increase the membership of the RDCRN. The public relations team hopes to see a 20 percent improvement in the monthly registration rate after the completion of the first year of the communications campaign. Increasing membership will help the organization reach more potential participants for clinical trials and medical studies, which will help each consortium progress towards finding a cure for its rare disease of focus. While it is impossible to reach every person suffering from each rare disease, it is important to reach as many people as possible.

### 2<sup>nd</sup> Objective

The second objective is to improve the communication efforts between the RDCRN and its publics by the end of the first year of the communications campaign. The public relations team would like to see one contact per month between each consortium and its registrants, and would also like to see the majority of registrants rate themselves as "very satisfied" with the services provided by their consortium and the RDCRN during the post-campaign survey. The RDCRN relies on its consortia members to fill clinical trials and medical studies and to provide insight into the diseases from a patient perspective. If the organization does not maintain good

communication with its members, registry members will be less likely to actively participate and offer their insights.

### **3rd Objective**

The third objective is to create a 100 percent increase the number of medical professionals who know about and support the RDCRN by the conclusion of the first year of the communications campaign, as measured by the number of medical facilities actively displaying or offering the RDCRN's marketing materials. Improving this aspect is critical for the success of the RDCRN and the campaign, because this is one of the weakest areas for the organization since no formal guidelines exist for reaching out to physicians. If the RDCRN meet this objective, it will see a direct correlation between increase in physician involvement and increase in member registration. The success of this portion of the campaign can be measured by comparing the number of medical professionals who supported the organization before the campaign started and comparing it to the number of medical professionals supporting the organization after the campaign is completed.

### **4th Objective**

The final objective is to improve the usability and appearance of the RDCRN website, so that finding the registry link takes less than 60 seconds in a usability test setting. Once the website has been updated and the improvements have been made, a second usability test will be conducted to determine if the changes made were beneficial. In order to receive accurate results, participants who took the usability test the first time would be asked to take the test a second time. It would need to be taken into account that these individuals will be able to navigate the website more easily upon second exposure, even if no constructive changes are made.

Once the campaign has successfully begun, it may be beneficial to create and distribute a midpoint survey to both the consortia members and medical professionals. Receiv-

ing feedback from the surveys would give the RDCRN an opportunity to evaluate its progress and discern whether its efforts are having the desired effect. If the midpoint evaluation shows that the campaign is helping the RDCRN to progress towards its goals, the registry may choose to devote more time, effort and money to implementing the plan to its fullest possible extent. If the midpoint evaluation reveals that changes are not being received well, the RDCRN may decide to conduct more extensive research to determine more specifically where improvements to their communication practices would provide the desired results.





# STRATEGIES

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The RDCRN's most pressing issue is efficient communication with its publics. Consortia have no structure to guide contact with their members, potential registrants are difficult to find and consortia leaders are often not aware that they have any resources available from the RDCRN. To correct these problems, the public relations team has divided the RDCRN's target audiences into three sections: professional publics, general publics, and internal publics.

Professional publics include all medical professionals, who have the potential to be a valuable resource for recruiting new registry members because of their relationships with patients. General publics include potential registrants, their friends and family and support groups. These publics may not have medical knowledge, but they have great need for up-to-date and useful information about the diseases that affect them, their friends and family and their members. Finally, internal publics include RDCRN registrants, the consortia leaders, and all other persons involved with the daily goings-on of the RDCRN. It is vital for these publics to remain connected to one another for purposes of mutual benefit and in order to retain registry members.

## Publics Addressed

### Professional Publics

#### -- Physicians/Disease Specialists

The most influential professional public is physicians, and more specifically, specialists who deal with certain diseases within the consortia that the network supports. Reaching out to doctors and disease specialists is vital to the success of the campaign primarily because they interact with and influence potential members. Patients look to this public for guidance and resources, making physicians and specialists the most credible recruitment tool for the RDCRN.

This public works with the patients first-hand, and is the first point-of-contact for recruiting members for the RDCRN.

#### -- Medical Office Staff

The nurses and administrative staff of medical facilities can be an influential professional public to reach out to for our campaign. This group can echo the information given to doctors about the RDCRN so that the doctors aren't the only public in the medical field knowledgeable about the registry and what it has to offer.

Targeting nurses, in conjunction with doctors, would most benefit the patients. If a doctor is unaware of the RDCRN, then the patient's second face-to-face medical resource will be their nurse. The nurses can also help to inform other medical personnel, which will create an even greater network of recruiters for the RDCRN.

The administrative staff can also be a very influential public to target because of the authority they have in a medical facility. By making the administrative staff aware of the RDCRN and the benefits of becoming a member, the staff can distribute information about the registry to the doctors and nurses so they can share that information with their patients.

### General Publics

#### -- Support Groups

Support groups should be targeted because not all of the medical professionals are directing their patients to the RDCRN. Patients join support groups for many reasons, but mainly because they want to connect with other individuals having a similar experience, to share information and have a supportive environment. Many individuals living with a rare disease are unaware of a clinical trial until they have heard about it through word-of-mouth via other support group members. It is essential to reach out to these members, since they may see the patients more than physicians do, and because support group leaders may often serve as an authoritative resource for patients.



Due the vast number of rare diseases and the fact that some diseases are rarer than others, it may be difficult to find enough individuals to establish a support group. However, the Internet has brought together people with rare diseases from around the world in a way that wasn't possible before, and we can target support groups on a global level. As the support groups can direct individuals to the RDCRN, the RDCRN can direct individuals to support groups as well.

**-- Potential Registrants**

Potential registrants are a difficult but vital public to reach. For each new member that is added to the registry, the patient consortium grows larger, creating more opportunities to participate in clinical research studies for that consortium, as well as bringing more attention to that specific disease. New registrants are arguably the most important public for the RDCRN to reach, but will most likely be contacted indirectly, through medical professionals and support groups.

**-- Families and Friends of Potential Registrants**

It is important to reach out to families and friends of potential registrants along with the patients themselves, as these people serve as the supporting network for many rare disease patients. By reaching out to families and friends, the RDCRN will create an even larger network of informed individuals who can spread the word about the registry and its services.

**Internal Publics**

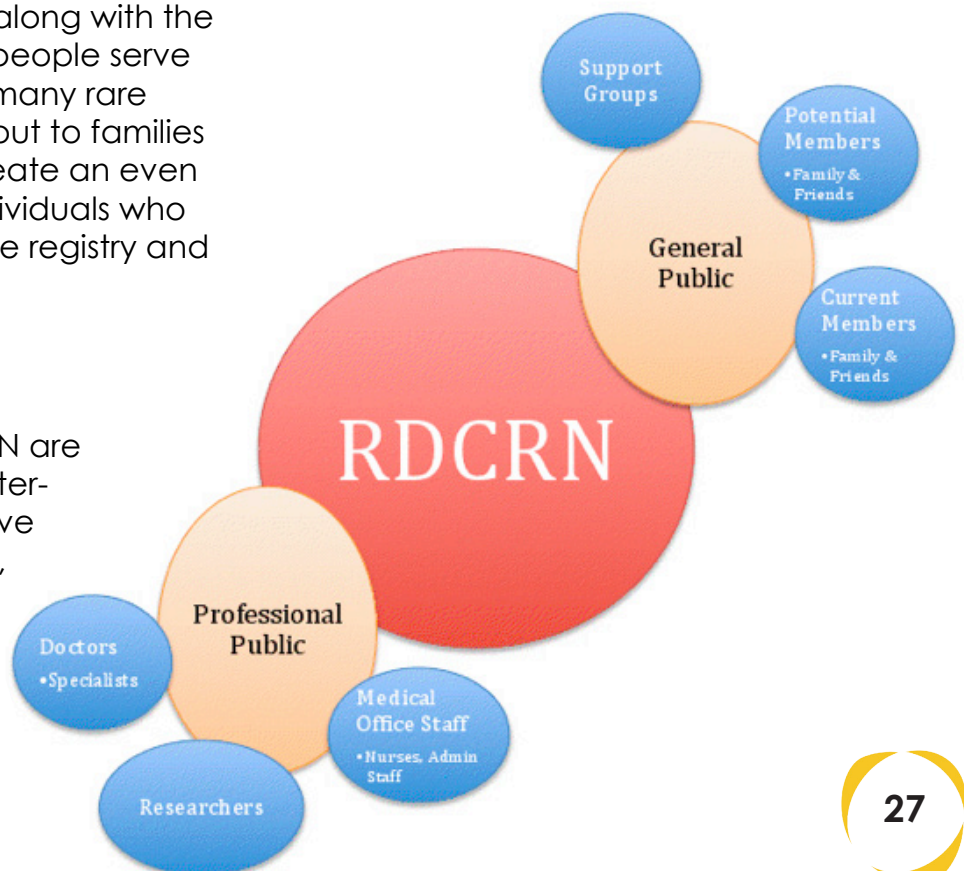
**-- Current RDCRN Members**

Current members of the RDCRN are perhaps the most important internal public to consider. They serve as the core of the RDCRN and, if the core is content and feels that communication is serving them well, then they will spread the word. No marketing or public relations tactic can generate more awareness than genuine third-party endorsements.

Being that this group is so important, it is important to understand what it wants, what it needs and what would specifically fulfill its needs. Once these needs are met, this group will be the very influential in serving the RDCRN and its mission of gaining new registrants.

**-- Families and Friends of Members**

The friends and family members of current registrants are almost as important as the current registrants themselves. Friends and family supplement the word of mouth marketing that is key in gaining new registrants for the RDCRN. Although the friends and family members are not the ones receiving the treatment or newsletters, they are in direct contact with the patients every step of the way. It is important that the registry treat friends and family of current residents with compassion, care and respect.



## Strategies

### Reaching Potential Registrants

By using a combination of both media and word of mouth channels to provide awareness and stress the importance of the RD-CRN, more potential members will become aware of its existence. Reaching out and using rhetorical appeals that combine both emotional and logical substance will persuade potential members to join. Using Aristotle's idea of persuasion (ethos, pathos, and logos), potential members will be persuaded to join because they will:

- see joining as the right thing to do
- feel emotionally motivated to join because they feel that someone other than themselves might benefit from that behavior
- think that joining is logical and that it simply makes sense to do so

### Media Relationships

Since the RDCRN is a non-profit organization, building partnerships with local and national newspapers or broadcast companies will benefit the organization. Building these relationships will help when the RDCRN needs to distribute news or promote the registry. Most media outlets have community service policies that can yield free publicity for an organization such as the RDCRN. Taking advantage of these policies, and doing so consistently, can foster relationships with reporters and media personalities that will potentially create more awareness for the organization.

### Press Releases

In utilizing these various media, the RDCRN can produce several forms of materials that will generate awareness for the organization. Press releases announcing any new developments, findings or larger clinical trials can be sent to both local and national publications. Press releases may also be sent to consortia to be featured as stories in their

newsletters as a way to remind patients of the registry and encourage them to remain involved. These releases should be distributed regularly, such as monthly or quarterly, and should focus on being timely, relevant and compelling. Focusing on awareness months for individual rare diseases and making them the focus of the releases may be one way to pique the interest of reporters.

### VNRs and PSAs

Outside of traditional press releases, the RD-CRN can produce video news releases and public service announcements for broadcasting new developments and membership recruitment messages. The video news releases can be produced to convey breaking news to potential members or serve as feature stories, and public service announcements can use a catchy opener to simply direct rare disease patients to the registry website. In addition, news websites can be utilized, as they often allow postings of various events on their websites, creating a cost-efficient forum for advertising local events and/or studies.

### Audience-Specific Media

The RDCRN can also produce informational articles to be distributed to audience-specific magazines, journals and online publications, such as a news wire or specialized websites about family health, etc. These articles can be distributed monthly or bi-monthly, highlighting only one rare disease or a group of related rare diseases each time. They can point the reader to the appropriate consortia for further information, and the RDCRN can be listed as the distributor, with RDCRN contact and website information included. The articles can usually be scheduled with a publication ahead of time based on the editorial calendar the publication has in place. These articles will help inform readers of the publications about the RDCRN, and will help to establish the registry and its consortia as leading authorities in the field of rare disease research.

## **Print/ Digital Materials**

Stories placed by the registry in an audience-specific magazine would offer communication directly to a specific target group. Audience-specific magazines would be easier to place stories in and magazines in general tend to have a longer shelf life when compared to other types of print media, as well as greater pass-along readership (when readers get the publication second-hand and without having to purchase it, such as when patients flip through magazines in the waiting room of a doctor's office).

Because the RDCRN has a limited amount of informational print materials available to its publics, its website serves as the publics' main source of information. The RDCRN needs to make all informational material (in both print and digital form) available online and also in other languages. This will make the registry more accessible to a larger population, which will lead to a growth in registry enrollment.

## **Community Involvement**

In addition to building partnerships with media outlets, creating opportunities for the RDCRN's community involvement will help grow awareness and membership for the registry. Being involved and active in the community through various mediums, such as community events, will help build credibility and reach out to publics that may have not been made aware of the RDCRN. Depending upon the type of event, the RDCRN can sponsor a booth, person participating in a walk, etc., to raise awareness of the registry. It is also possible for the registry to sponsor its own event, such as a softball game, 5K or other family-friendly event, to attract registrants and build community support. For events and opportunities that the RDCRN may not be able to attend, a liaison may be considered to represent the registry.

**Communicating with Current Members**  
By using a combination of interactive media such as surveys, and in-person communication programs such as focus groups, the RDCRN can receive direct feedback from

its members that can be used to increase and improve its communications efforts. Conducting these various research methods and enabling two-way communication will further improve the functionality of the registry and its relationships with its patients and consortia. The more information the registry is able to extract from the feedback, the easier it will be for the registry to pinpoint exactly how it can better serve its patients and consortia.

## **Social Media**

Social media can be an effective tool in keeping in touch with current members because of its speed, ease of use and facilitation of two-way communication. Creating pages on Facebook and Twitter would allow for communicating the most current information and would also serve as a forum for two-way communication with those who are connected with the registry through these outlets. Users can comment on posts, send messages or share their own ideas with the registry on these sites. It may be possible to ask the consortia that have social networking sites to add a link to the RDCRN networking sites in order to create cohesion and an even larger forum for communication.

## **Newsletters**

Newsletters are also a great way to stay in contact with current registrants and keep them up-to-date with ongoing projects, new developments and the latest registry news. These newsletters can also include feature stories, like a motivational piece about a patient or an inspirational message, to help patients feel as though they're not forgotten. Sending these to the registrants on a monthly or quarterly basis will help them feel as though they are being communicated with regularly instead of only once or twice a year.

## Communicating with the Consortia

Communicating with the consortia is vital to retaining the current membership of the registry. If the RDCRN becomes proactive in its communication with its consortia, consortia will likely mirror that behavior with their members, making them more likely to remain interested and involved. This would result in a more positive relationship between members, their consortium and the RDCRN.

## Reaching the Medical Audience

Another public that is critical in raising awareness and directing rare disease patients to the registry is the group of individuals that comprise the medical field: doctors, nurses, physicians assistants, etc. This public works one-on-one with patients and is a critical source of information, as they can serve as a direct link between the patient and the registry by making patients aware of and referring them to the registry. In order to reach the medical audience on a professional level, it is important to create materials tailored to them specifically.

## Case Studies

One way of tailoring materials specifically toward the medical audience is by providing case studies. These can either be tangible (paper form) or in electronic form and can be sent to the physicians on a quarterly basis. By including a boilerplate with biographical information about the RDCRN in each study, physicians will be constantly reminded of who is providing the information; this will allow for consistent awareness of the registry. In order to keep the medical audience interested, it is important to focus the studies on a variety of topics such as:

- *Success stories: focusing on one or two patients whose lives have been changed due to the work of the RDCRN. These can include those who have taken part in a clinical study, found others with their rare disease through*

*the registry or any other story that is patient-centric. This will provide a testimonial for the work that the RDCRN does and how that work helps patients.*

- *Rare diseases: putting a focus on a specific rare disease draws attention to a medical issue that has little exposure on an everyday basis. The uniqueness of the topic can help the case study bypass the noise of the typical medical issues frequently seen, piquing interest and increasing the chances of positive exposure to this public. Once physicians and the public become more aware, the disease can be recognized and treated more effectively and more individuals afflicted with the rare disease can be identified. This will also assist physicians in becoming more knowledgeable about these rare diseases and better equipped to speak with patients who have been diagnosed.*

- *New developments: keeping medical professionals informed about results of new clinical studies, new developments in treatments resulting from the studies, or other industry-specific changes keeps the medical professionals up-to-date with the newest information in the rare disease branch of medicine. These case studies could focus on new rare disease medicines in the works, new technology or improved procedures in treatment.*

## Speaking Engagements

Another way to educate the medical audience about the RDCRN would be to speak to them at seminars or events they may be attending. Targeting a seminar or event tailored to rare diseases in general or an event for a specific disease where doctors will be in attendance could give the organization a chance to speak directly to the physicians, as well as give the RDCRN the power to reach many doctors at one time. This method would require materials for presentation on part of the RDCRN. Some ideas may include:

- *A representative speaker who works for the RDCRN to explain the registry and why it is*

important to get patients involved.

-- A patient advocate who has been helped by the registry and can share his/her story.

-- Hard facts about a specific rare disease presented on a PowerPoint presentation along with handouts, brochures and any other tangible materials that doctors could take with them to remember the information and know how to take further action.

## Obstacles

### Potential Problems

Obstacles for the RDCRN can be sorted into the following categories: accessibility; publicity and overall recognition of the RDCRN and its purpose; patient benefits and continued interest.

Examples of obstacles in each category include:

### Accessibility

-- How can the website be designed in such a way that it's easy and effective to use, and also written in language that can be understood by general publics and patients?

-- How can the RDCRN create face-to-face experiences for potential registrants who may be uncomfortable with the online format of the registry?

-- Are advocacy groups and medical professionals willing and prepared to hand out information kits and help with national events?

### Publicity

-- How will the RDCRN create a consistent and efficient plan to publicize the organization's purpose and intent?

-- Is each consortia individually prepared for the potential increase in media coverage their respective rare disease will receive?

-- Is the RDCRN as a whole prepared for potential negative media coverage that may be received?

-- Is the RDCRN and each consortium involved ready to educate uninformed publics about each rare disease if necessary?

### Patient Benefits

-- People may very well take a "what's in it for me?" attitude about joining the registry. The RDCRN has to be able to make the value of registering clear to potential registrants.

-- Does registering with the RDCRN actually result in progress being made toward the treatment and possible cures of rare diseases? Potential registrants may be frustrated with the medical assistance they've received thus far, and may want proof that the registry is trustworthy.

-- The RDCRN needs a way to inform the public when a new rare disease consortium joins the registry. Otherwise, new consortia will have a difficult time with recruitment of members.

### Continued Interest

-- Once a patient joins the registry, they may ask themselves, "Well, what now?" The RDCRN must be able to continually keep the registrants engaged and empower them by offering them options.

-- What is the RDCRN going to do to keep registrants interested in their organization?

-- How is the organization going to prove to registrants and medical professionals that being associated with the organization is a continued benefit to them?

### Money

-- How much money will it cost to execute the campaign?

-- From where will funds to execute the campaign come?

-- How will the RDCRN prove to donors and grant distributors that the money the RDCRN is receiving and putting toward the cam-

*campaign is being used in the most beneficial way?*

### **Potential Audience Issues**

As mentioned previously, there are various obstacles that could occur during this campaign. While we don't see why medical professionals would choose not to contribute or participate in the registry, often they are so busy that they don't take on anything out of the normal scope of their work. If medical professionals do not help in this effort, suffering patients will not be fully informed of the potential help that is available to them.

In addition, the internal publics of the RD-CRN (consortia leaders and staff) may resist following campaign guidelines if not properly informed of the campaign's intent or convinced of its viability. They may also lack manpower to execute the recommendations made by the public relations team. It is the responsibility of the RDCRN to ensure that all participants in this campaign are fully informed and given the proper tools to move forward.

### **Avoiding Obstacles**

To avoid the obstacles outlined above, the RDCRN can be proactive about addressing concerns raised by its various publics and about improving its services. Since doctors may be busy and distracted, the RDCRN can provide them with attractive marketing materials to place in their waiting rooms so that patients can access information about the RDCRN without the doctor's help. Also, the registry can provide additional packets of information in case patients ask about the RDCRN. This will allow administrative staff to offer the extra materials to potential registrants without needing to make any major time investments to do so.

To encourage internal publics to adhere to the communications campaign, the registry can send an email memo to its staff informing them about the campaign, its importance and

ways that they can help facilitate its success. To overcome possible issues with lack of manpower, the public relations team has suggested hiring a part-time public relations coordinator to assist the registry staff and consortia leaders in preparing newsletters, placing stories, interviewing subjects for articles, contacting media, etc. While this added financial burden might seem undesirable, the public relations team believes that, long term, the improvement in communications will create vast improvements for the registry as a whole, making it a stronger competitor for federal grants and private research funding.









# TIMETABLE

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## Campaign Start

**Monday, January 2, 2012**

## Campaign End

**Monday, December 31, 2012**

### Pre-Campaign

- Plan content for first newsletter. Gather necessary information, conduct interviews and begin crafting stories.
- Gather information needed to update the following:
  - brochures and fliers
  - patient advocacy group information packets
  - physician and registrant packets
- Determine events to participate in nationally, including conferences, workshops, rallies, etc. Contact event coordinators as needed to obtain space, speaking opportunities or tickets.
- Finalize newsletter content and layout. Submit for final edits and approval.
- Finalize updated brochures, fliers, packets, etc. Send to printer.

### January

- Release an "opening" newsletter via e-mail. Newsletter will be released the first week of every other month, on Wednesday. Items to cover include: [week 1]
- Campaign goals and objectives
- Success stories
- Grants (new and incoming)
- "Physician Spotlight"
- Upcoming events; event calendar; "Awareness Dates"
- Giving opportunities
- Newsletter content should be compiled 3rd week of the month for the next month's newsletter.
- Some newsletter content can be re-used

for press releases.

- Release updated brochures and fliers [week 1]
- Distribute new registrant packets and physician packets [week 1]
- Begin distribution of updated patient advocate information packets [week 3]
- Confirm website updates are implemented for campaign. Updates to the site will be an ongoing task throughout the entire campaign.
- Fliers should be sent out 10-14 days before any scheduled events. There are no specific dates for events at this time, however, the RDCRN can assign fliers to be made as events are randomly scheduled. If an event pertains to a specific consortia, that consortia should send out fliers.
- Press releases will be distributed as appropriate, such as in the event of new research discoveries, addition of new consortia, etc. The RDCRN should try to release at least one press release per month. Some newsletter content can be re-used for press releases.
- Release the updated RDCRN brochure. Only one brochure is necessary for the year, as the RDCRN has limited resources for creating the materials.
- Plan postcard content and conduct necessary research and/or interviews.

### February

- Finalize postcard content and layout.
- Begin release of bi-monthly postcard. Postcard will highlight new and ongoing research and important updates for patients. The postcard is registry-specific. Postcard will be distributed the second week of every other month, on Monday. (February, April, June, August, October and December). [week 2]
- Plan content for newsletter. Gather necessary information, conduct interviews and begin crafting stories.
- Finalize newsletter content and layout. Submit for final edits and approval.

## **March**

- Release newsletter for March.
- Plan postcard content and conduct necessary research and/or interviews.

## **April**

- Finalize postcard content and layout.
- Release postcard.
- Plan content for newsletter. Gather necessary information, conduct interviews and begin crafting stories.
- Finalize newsletter content and layout. Submit for final edits and approval.

## **May**

- Release newsletter for May.
- Plan postcard content and conduct necessary research and/or interviews.

## **June**

- Finalize postcard content and layout.
- Release postcard.
- Plan content for newsletter. Gather necessary information, conduct interviews and begin crafting stories.
- Finalize newsletter content and layout. Submit for final edits and approval.

## **July**

- Release newsletter for July.
- Plan postcard content and conduct necessary research and/or interviews.

## **August**

- Finalize postcard content and layout.
- Release postcard.
- Plan content for newsletter. Gather necessary information, conduct interviews and begin crafting stories.
- Finalize newsletter content and layout. Submit for final edits and approval.

## **September**

- Release newsletter for September.
- Plan postcard content and conduct necessary research and/or interviews.

## **October**

- Finalize postcard content and layout.
- Release postcard.
- Plan content for newsletter. Gather necessary information, conduct interviews and begin crafting stories.
- Finalize newsletter content and layout. Submit for final edits and approval.

## **November**

- Release newsletter for November.
- Plan postcard content and conduct necessary research and/or interviews.

## **December**

- Begin updating marketing objectives for next calendar year. [entire month]
- Send out a “Happy Holidays” postcard.
- Plan content for newsletter. Gather necessary information, conduct interviews and begin crafting stories.
- Finalize newsletter content and layout. Submit for final edits and approval.





# EVALUATION & CONCLUSION

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## Evaluation

The success of this campaign can be evaluated using two primary methods. After the implementation of the campaign, the following will be monitored and compared to original research data:

- *The rate of registration to the registry, to determine if an increase in registration was achieved*
- *Registry member and consortia leader satisfaction with communication efforts, as measured by survey instruments provided by the public relations team*

The evaluation of these measures is pivotal in keeping a clear campaign direction and determining whether the primary goals of the RDCRN have been met. In addition, it allows those involved in the campaign to distinguish what strategies are or are not working, giving the public relations team a chance to modify and improve the campaign and to build better future communications campaigns.

Methods of evaluating the campaign will be very similar to the initial steps taken in collecting research data. These include:

- *Online surveys*
- *Website usability test*
- *Interviews with focus group participants or focus group*

Using the same or similar evaluation methods allows the comparison of like data sets taken at separate times: prior to campaign implementation, during the campaign and after it has concluded. Multiple measures will make it much simpler to evaluate and determine the campaign's success.

## Evaluation Criteria

The intention of the public relations team is to reuse the research instruments from the beginning of the campaign to evaluate the success of the communications plan during the campaign's implementation and then again after its completion. By revising the original instruments, we can gather like data with which to compare the registry membership numbers and registration rates, and satisfaction levels of its publics before, during and after the communications campaign was implemented.

Communication with consortia leaders is also a major concern for the registry. To reflect this, the campaign suggests ways of creating and maintaining relationships with consortia. The communication among employees, members and consortia wasn't structured, and many consortia leaders were unsure of what services the registry provided to them. To evaluate the success of the communications campaign at addressing these issues, we will again look to the original survey instruments to be revised and re-administered. The data collected will allow the registry to determine if its staff and consortia leaders are satisfied with the intra-organizational communication.

The evaluation criteria address the registry's main concerns, and then all measures for evaluating these criteria have been engineered specifically for that purpose. The surveys asked registry members and consortia leaders to identify what they liked or disliked about the registry, the focus group gathered more detailed information on the same topics from consortia leaders and physicians, and the usability test evaluated the issues with the website. Each of these measures ties back to the goals of increasing registry enrollment and retention and improving communications with the registry's internal publics.

## Analysis

The collection of midpoint and post-campaign data will allow the RDCRN to look at the campaign as though it were an experiment. The initial data serves as the control, while the midpoint and post-campaign measures offer varied levels of independent variable application (campaign strategies). Though this is not an actual experiment, looking at the campaign in this way will allow the RDCRN to evaluate its success in a more measurable way, and may give the registry a better chance of gaining federal funding by offering visible, measurable results.

To analyze the data, the RDCRN can either use software they already have available for their research, or can use Minitab 16, a leading statistical software for quality improvement, which offers components that allow users to monitor processes over time and evaluate their stability. Minitab is often used in Six Sigma, the world's leading quality improvement methodology. Currently, 450 companies in the Fortune 500 use and recommend this product. Minitab will prove to benefit RDCRN by interpreting statistical data to make informed decisions in the future.

## Conclusion

In our detailed public relations plan for the RDCRN we have outlined the strategies we feel appropriate to implement in order to help the organization meet its goals. After conducting thorough research on the desired target audiences, analyzing results and applying our best judgment, we are confident our suggestions will allow the RDCRN to actualize its desire to expand its disease registry while simultaneously strengthening its relationships with currently registered members to fulfill the ultimate goal of discovering cures for rare diseases.

Current roadblocks standing between the RDCRN and its goals include lack of communication between publics, limited patient use of registry, the unique challenge of connecting with people with rare diseases,

lack of two way communication and inadequate and outdated communication and information dispersion. In an effort to ameliorate these problems we put together a specialized public relations plan tailored to achieving the RDCRN goals of improving the quality of contact with consortia members, standardizing frequency of contact with consortia members, increasing the number of medical professionals who know about and support the RDCRN and improving the usability and appearance of the RDCRN website.

In order to realize these goals, three specific publics have to be addressed including professional publics (such as physicians, disease specialists and medical office staff), the general public (consisting of support groups, potential registrants and families and friends of potential registrants) and internal publics (including current RDCRN members and families and friends of members).

Strategies for successfully reaching out to the professional medical publics include providing them with case studies focusing on topics such as success stories, rare disease information and new developments as well as engaging them in speaking events where they can learn more about the RDCRN. To reach the general public, it may be more beneficial to target them through properly placed media in the form of video news releases and public service announcements secured through the development of strong media partnerships/relationships and the use of press releases to disseminate information. Other effective strategies include garnering awareness and interest through community involvement, placement in audience-specific media and use of print and digital materials. To reach internal publics it is vital to employ social media, specially tailored newsletters and ensure communication with consortia.

In order to remedy the problem of poor website usability, please see the detailed findings discovered during the usability test the public relations team performed. A few notable issues which need correcting are the site's organization, lack of structure, information overload, layout design and lack of both focal point and white space.

To measure the success of our plan, the public relations team has outlined suggested objectives. We would like to see a 20 percent improvement in the monthly registration rate after the completion of the first year of the communications campaign, have registrants rate themselves as "very satisfied" with the services provided by their consortium and the RDCRN during the post-campaign survey, create a 100 percent increase the number of medical professionals who know about and support the RDCRN by the conclusion of the first year of the communications campaign and improve the usability and appearance of the RDCRN website, so that finding the registry link takes less than 60 seconds in a usability test setting. If the strategies detailed in our public relations plan are applied, we have no doubt the RDCRN can reach its goals and improve the state of the organization.









# APPENDIX A: Research Materials

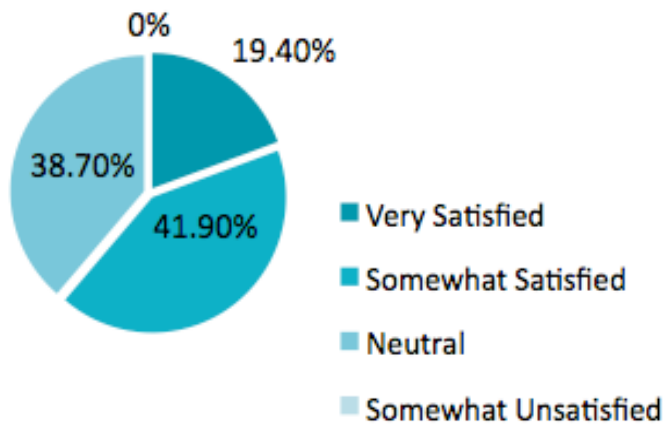
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## Research Findings (Cont. from Report)

We had 37 members respond to our survey. The overall perception of the UCDC is positive; however, there are some improvements that would benefit the registrants. First, when asked how easy it was to fill out the registry's online forms, 46.9 percent said it was somewhat easy. Only 40 percent said it was extremely easy.

Secondly, when asked, "How satisfied are you with the services provided by the UCDC", 41.9 percent said they were somewhat satisfied.

### Q 18.



Lastly, below are the results from our question 16. This question is important because it presents how the patients feel their communication level is with the UCDC. Over half, at 53.7 percent, said that there needed to be a slight increase in communication.

The data collected from this survey suggests that our objectives should include increasing the usability of the website and increasing the communication level between the UCDC and its members.

## Research Questions/Hypotheses

### Questions

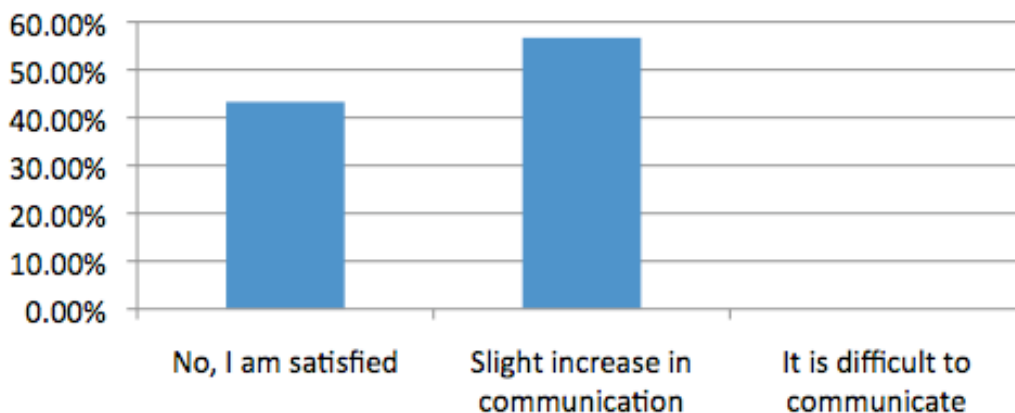
Q1: What do members already see as problems for the RDCRN?

Q2: What improvements could be made to increase RDCRN member satisfaction?

Q3: Which recruitment methods are the most effective and how can they be made to be more effective?

Q4: What changes to the website would make it easier to use?

The four questions above are important to answer in order to support enrollment and to maintain active members of the contact registry. Planning specific communications tactics to address the problems revealed during research will allow the network to better serve its publics and to develop a reputation as a valuable resource for rare disease patients, researchers and doctors.



## Physician Survey Results

1) What is your role within the RDCRN?  
(59 responses)

Answers:

Response Count

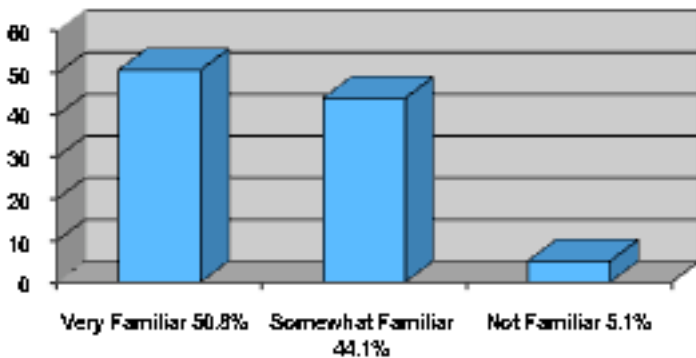
Principal investigator of an RDCRN Consortium 11.9% 7

Physician Investigator in an RDCRN Consortium 40.7% 24

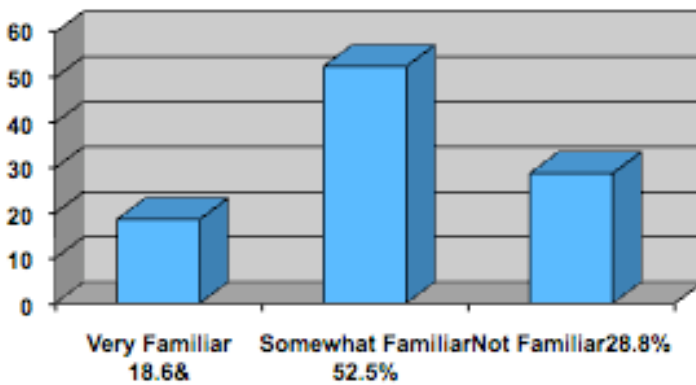
Clinical Coordination 27.1% 16

Other (please specify) 20.3% 12

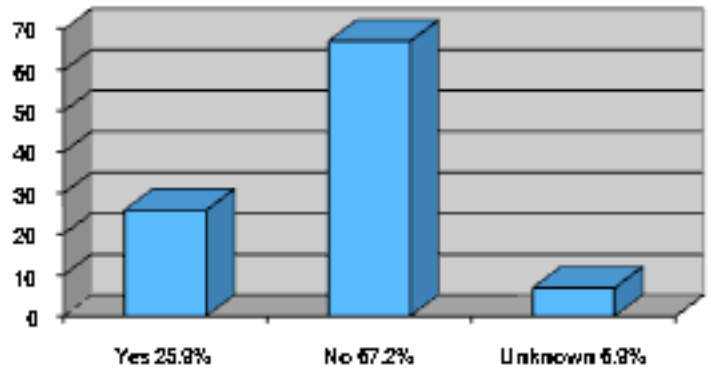
2) How familiar are you with the RDCRN?  
(59 people answered)



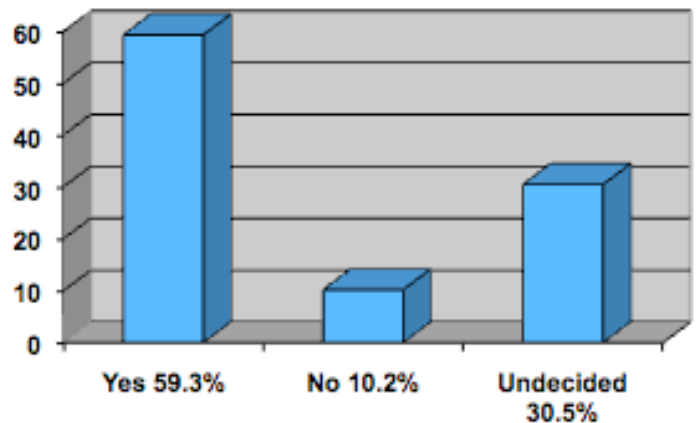
3) How familiar are you with the RDCRN Contact Registry?  
(59 people answered)



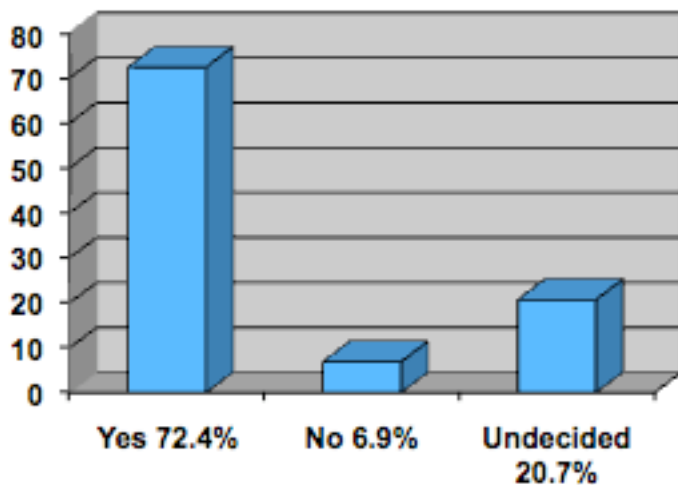
4) Do you currently provide education materials about the RDCRN Contact Registry to your patients?



5) If new information became available about the rare disease with which you are affiliate, would you use the RDCRN Contact Registry to share the information?

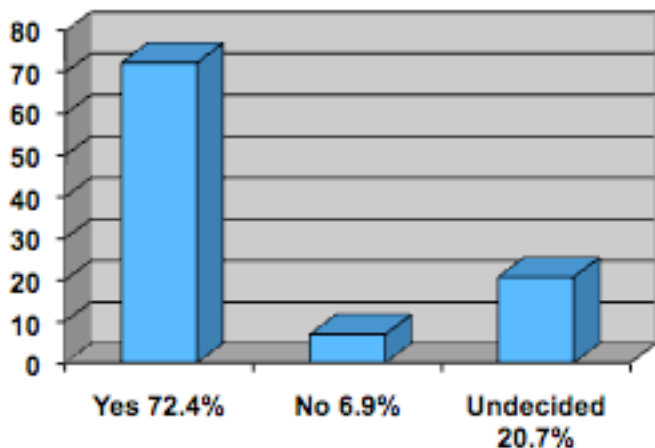


6) If there were clinical trials in your geographic area for which your patients might be eligible, would you use the contact registry to inform them?



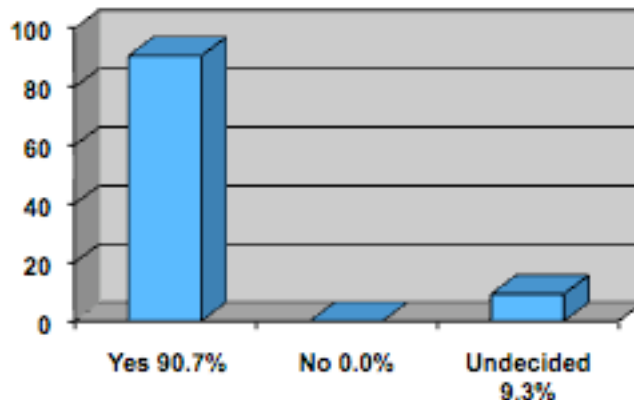
7) If there were clinical trials in your geographic area for which your patients might be eligible, would you use the contact registry to inform them?

(58 people answered)



8) Tools like the RDCRN Contact Registry connect people with rare diseases, notify them of clinical trials and inform patients about educational resources and activities? If you indicated earlier that you do not use the contact registry, would you promote a resource like this to your patients?

(54 people answered)



Comments from participants:

"The RDCRN contact registry is a nice idea, but it is unclear how this effort interfaces efficiently with the PAGs and investigators it is supposed to help."

"I am working in Italy, therefore the Contact Registry usefulness for our patients is limited by language and geographical reasons."

"I would appreciate even more information about other studies that are in the RDCRN and how I can refer my patients to those other studies (outside of my primary study). Right now, I don't feel there is any effort in this area."

"The reason why I don't use the registry as much is because I know the main support group websites by heart, and I know patients will get information from there. I verbally inform patients about the clinicaltrials.gov website for clinical trials information."

"Although I am a PI in the Consortium, I've never been taught how to connect or use the registry. Maybe this is my fault, but I never thought to ask because I was not aware that I would have access to it. Thanks for the survey. I learned something."

"How does the Contact Registry connect peo-

9) If answered yes to the previous question, in what ways would you be willing to promote it? (Select all that apply) (53 people answered)

| Answers                                       | Percent | Responses |
|-----------------------------------------------|---------|-----------|
| Brochures in office                           | 69.8%   | 37        |
| Telling patients about the registry           | 86.8%   | 46        |
| Informing other physicians about the registry | 64.2%   | 34        |
| Participating in RDCRN activities             | 45.3%   | 24        |

ple with rare diseases? Maybe there is a feature that the UCDC is not using? If so, please let us know how to do so. Thanks “I quite often will get duplicate emails regarding the same person. Many times, the emails are sent at the same time.”

### Usability Test

#### RDCRN website findings

- Cluttered
- Unorganized
- Lack of structure
- Layout design affects readability
- Information overload
- There isn't a focal point to guide through the website
- Lack of white space, causes the website to look dense
- Many links direct users to the registry form, which causes confusion

#### Subjects

1. Male, Caucasian age 23, some college

#### Complaints

- Frustrated with navigating through website

- Overuse of fine print
  - Too much of information to read
  - After 1:46 minutes, the subject was able to find the correct link to join the registry
  - Registry form is poorly constructed. Name and contact information should be listed first.
  - The icons for each consortia on the website distracted the subject from seeing the “register now” link
2. Female, Caucasian, age 26, pursuing a MA
- #### Complaints
- Information overwhelming
  - Confused
  - After 1:47 minutes, the subject was able to find the correct link to join the registry.
  - “Join the registry” link isn't prominently placed on the website

## **Research Materials**

### **Patient Cover Letter**

Dear RDCRN member,

The advanced public relations students in the School of Mass Communications at the University of South Florida are collecting data to assist the creation of a communications campaign on behalf of the Rare Disease Clinical Research Network. The RDCRN seeks to improve their relationships with registered members, expand member and physician data and enhance recruitment to potential members.

Please take a few moments to complete the following survey, containing multiple choice and open-ended questions. Your answers will give us information to evaluate problems you see in the registry and how we can assist in increasing member satisfaction.

Thank you,

Public Relations Students at the University of South Florida

### **Physician Cover Letter**

Dear Physician,

The advanced public relations students in the School of Mass Communications at the University of South Florida are collecting data to assist the creation of a communications campaign on behalf of the Rare Disease Clinical Research Network. The RDCRN seeks to improve their relationships with registered members, expand member and physician data and enhance recruitment to potential members.

Please take a few moments to complete the following survey, containing multiple choice and open-ended questions. Your answers will help the RDCRN to improve relationships and communication with physicians, thereby providing better service to patients.

Thank you,

Public Relations Students at the University of South Florida



## Survey Instrument

Thank you for taking the time to complete this survey. As a member of the Rare Disease Clinical Research Network (RDCRN), your feedback is important and will assist in better understanding how to improve the services provided by the RDCRN. This survey should only take about 10 minutes of your time and your answers will be completely anonymous. We appreciate your time and feedback. Thank you!

Please choose the best answer.

1) Approximately how long after being diagnosed with your rare disease did you learn of the Rare Disease Clinical Research Network Registry (RDCRN)?

- A) Same day
- B) Less than one month
- C) One to three months
- D) Four to six months
- E) Seven months to one year
- F) One year or more

2) How did you first learn about the RDCRN Registry?

- A) Physician or medical provider
- B) Internet search
- C) Word of mouth
- D) Patient advocate/Patient Advocacy Group
- E) Other (please specify): \_\_\_\_\_

3) After finding out about the RDCRN Registry, about how long did you wait before registering?

- A) Less than one day
- B) One day to one week
- C) One to three weeks
- D) More than three weeks

4) How easy would you say it is for you to navigate the RDCRN website?

- A) Extremely easy
- B) Somewhat easy
- C) Neither easy nor difficult
- D) Somewhat difficult
- E) Extremely difficult

5) Approximately how long did it take you to find the registration form from the home page of the registry website ?

- A) Less than one minute
- B) One to four minutes
- C) Five to 10 minutes
- D) More than 10 minutes

6) How easy would you say it was for you to fill out the RDCRN's online forms?

- A) Extremely easy
- B) Somewhat easy
- C) Neither easy nor difficult
- D) Somewhat difficult
- E) Extremely difficult

7) Please rate the level of difficulty you experienced while answering the questions on the registry application. (Scale: 1 = No difficulty, 10 = Extreme difficulty)

1    2    3    4    5    6    7    8    9    10

8) Did any of the application questions asked make you feel uncomfortable as far as your privacy?

- A) Not at all
- B) Some questions
- C) Many questions

9) If you answered that some or many of the questions did make you uncomfortable, which questions do you feel should not have been asked? \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

10) How long did it take you to complete the questions asked on the application?

- A) Less than five minutes
- B) Five to 10 minutes
- B) 11-15 minutes
- C) More than 15 minutes

11) Please rate the ease of use of the RDCRN registration process. (Scale: 1 = Extremely easy to use, 10 = Extremely difficult to use)

1    2    3    4    5    6    7    8    9    10

12) How often are you contacted by the RDCRN?

- A) Less than two times a year
- B) Three to four times a year
- C) Five times a year or more

13) How often are you contacted by your consortium?

- A) Less than two times a year
- B) Three to four times a year
- C) Five times a year or more

14) Which of the following most accurately reflects your feelings about the level of contact you have with the RDCRN?

- A) I feel that the RDCRN does not contact me often enough.
- B) I feel satisfied with the level of contact I have with the RDCRN.
- C) I feel that the RDCRN contacts me too often.

15) Which of the following most accurately reflects your feelings about the quality of information provided to you by the RDCRN?

- A) I feel that the information I receive is helpful and relevant.
- B) I feel that the information I receive is not relevant and less than helpful.
- C) I'm not sure how I feel about the quality of the information I receive.

16) When you want to contact someone at your consortium, how easy is it for you to get in touch with the person with whom you need to speak?

- A) Extremely easy
- B) Somewhat easy
- C) Neither easy nor difficult
- D) Somewhat difficult
- E) Extremely difficult
- F) Never attempted to contact

17) Do you feel there is a need for better communication between the RDCRN and its registrants (you)?

- A) No, I am satisfied with the level of communication.
- B) A slight increase in communication is necessary.
- C) It is very hard to communicate as a member of the registry and I feel the current communication needs improvement.

18) If your rare disease is supported by an advocacy group, how helpful do you feel they are with relaying information?

- A) Very helpful
- B) Somewhat helpful
- C) Somewhat unhelpful
- D) Very unhelpful
- E) I'm not sure
- F) There is no advocacy group supporting my disease.

19) How satisfied are you with the services provided by the RDCRN?

- A) Very satisfied
- B) Somewhat satisfied
- C) Neutral
- D) Somewhat dissatisfied
- E) Very dissatisfied

20) How satisfied are you with the services provided by your consortium?

- A) Very satisfied
- B) Somewhat satisfied
- C) Neutral
- D) Somewhat dissatisfied
- E) Very dissatisfied

21) In making improvements to the RDCRN, rank the following based on what you think should happen first.

(Use the numbers 1 - 4, where 1 = "Most important" and 4 = "Least important.")

- \_\_\_ Make the RDCRN website easier to navigate.
- \_\_\_ Increase contact between the consortia and their members.
- \_\_\_ Provide a way for consortia members to interact with each other and share stories and information.
- \_\_\_ Create a way for members to share medical records to get a second opinion on their diagnosis.

#### RDCRN Physician Survey

Thank you for taking the time to complete this survey. Your feedback is important and will assist in better understanding how to improve the services provided by the Rare Disease Clinical Research Network. This survey should only take about 5 minutes of your time and your answers will be completely anonymous. We appreciate your time and feedback. Thank you!

1) How familiar are you with the Rare Disease Clinical Research Network (RDCRN)?

- Very familiar
- Somewhat familiar
- Not familiar

2) If you are familiar with the RDCRN, how did you hear about it?

---

3) Where do you research information on rare diseases? (Circle all that apply)

- Internet
- Books
- Databases
- Medical Journals
- Other (Please specify): \_\_\_\_\_

4) If a patient wanted more information about their rare disease, would you supply it if you had the tools?

- Yes
- No
- Undecided

5) If a patient was concerned about finding other people with their rare disease, would you help if you had a place to direct them?

- Yes
- No
- Undecided

6) If there were trials held locally that your patients could attend, would you inform them?

- Yes
- No
- Undecided

7) Would you mind providing rare disease brochures for patients in your waiting room?

- Yes
- No
- Undecided

8) Registries like the RDCRN connect people with rare diseases, notify them of trials and inform patients. Would you promote an organization like this to your patients?

- Yes
- No
- Undecided

9) If you answered yes to the previous question, in what ways would you be willing to promote it? (Circle all that apply)

- Brochures in office
- Telling patients about the registry
- Informing other physicians about the registry
- Participating in RDCRN activities
- Other (Please specify): \_\_\_\_\_

Do you have any suggestions and concerns you would like to direct to the RDCRN? If so, please do so here: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

## **Focus Group Questions**

How did you find this registry?

Does your advocacy group recruit members or individuals or do they have to find a way to contact your organization?

What are some current strategies that you use to attract members or how have they contacted you?

How long has the advocacy group been active?

How motivated are the individuals in your advocacy group to find others with the same rare disease?

Do you provide a way for members to communicate with one another?

In what events does your advocacy group engage?

How do you engage with the group?

Are any forms of social media used to communicate with the public?

What are the major concerns of the advocacy group?

Name one goal that has been difficult to achieve for your group?

How has this process, with the advocacy group and being a member of the registry, helped you?

Are there members who become hopeless and lose interest?

Are there some changes you would like to see happen with the registry that would possibly help recruit more members?

## References

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- O'Neal, J. (2009). Research methods in public relations practice. Retrieved from <http://www.slideshare.net/jackie57>
- Research topics. (2011). Retrieved from <http://www.instituteforpr.org/research/topics/>

## **Focus Group Minute Notes**

*How did you become involved with this registry?*

Involvement was highly encouraged, but not mandatory.

Jennifer – requires members to be involved

Joyce- Patient Advocacy group the VCRC

ED B. – Patient Advocacy group the VCRC

*Does your advocacy group recruit, or do patients have to find a way to contact your organization?*

Joyce and Ed actively recruit, as does Steve. Steve uses social media, events, walks, etc.

Joyce- Recruitment is a big deal through efforts such as newsletters, websites & chat boards

Steve- Does outreach through blogs & social media. Open Source technology allows friends that can only contact friends in the network and they can also be individually tracked

*What are some current strategies that you use to attract members or how have they contacted you?*

Brochures are important to help inform patients. Direct mailers to new patients keep them in the loop about the registry. All the staff are aware that the No. 1 goal is to recruit to the registry.

ED-PAN Attract web & Facebook. 70% of its member comes from the VACA website. Registrants are made aware of their registration right after they join.

Jennifer- Gives out brochures at medical clinics to inform patients about the registry.

ED- Does direct mail, and every new patient gets a brochure.

Steve Turner- Gives patient surveys to incoming patients to share information. Assigns case workers to help patients get more information, as most of the time they cannot complete the forms.

*How motivated are the individuals in your advocacy group to find others with the same rare disease?*

Joyce Coleman- Patients are very motivated to join Facebook & message boards.

ED- Same as above; also says the main reason is to talk to someone else who has disease.

Steve- Adult patients are less motivated in social networks. Parents of kids are more motivated.

*Do you provide any way for patients to communicate with one another?*

Peer support is good, especially for new people. Physicians chat online with patients. People like to meet online, then in person. Net care- patient support website

Steve- Patients can send friend requests on their own face chat.

ED- Peer support, list of members willing to talk to new people. Those people are a mix of new people and medical provider's patients.

*In what events does your advocacy group engage?*

Partner with matching patients with groups.

Ed- 90% of interaction is through Yahoo groups and special events.

*What are the major concerns of the advocacy groups?*

After diagnosis, groups need to find patients as quickly as possible. Registry members seem to want a lot more contact than they're getting. Often, there are no other research studies available to them besides the ones affiliated with the registry. Also, patients often have special diets they have to follow and other lifestyle restrictions. Newsletters about those topics would help them stay healthy and remain actively engaged with the registry.

Steve- The biggest issue is patients who have been diagnosed with the disease too long to treat, and therefore too late to partake in new research

ED- Once they signed up, patients didn't receive follow-up and thought they were dropped from the study or were under the impression that they were being included in the studies when they were not. Perhaps publishing once a month newsletters for each disease would help to keep members up to date.

Name one goal that has been very difficult for your consortium to achieve.

Debbie- More aggressive recruiting for clinical encounters

Steve Turner- has issue with information going into registry and if it's good enough.

ED- Show how the data has real world application.

Do members ever become hopeless or loose interest?

ED- Yes, two reasons: Patients are doing well and don't want to make others feel bad that they may not be, or patients are doing poorly and don't want to be negative or bring others down.

*Are there changes you would like to see happen with the registry that would possibly help recruitment?*

Joyce- Would love to expand to patients with other diseases not listed, and have them be notified when the registry is available. Patients often become discouraged if no study is being done, so offering that to them would help them feel less neglected.



## Method

### Data Collection Techniques

Due to the scattered nature of the population from which we collected data, and the time limits associated with this project, we surveyed existing members of the RDCRN instead of looking for potential members. The limited size of and the lack of information available to identify this elusive population would have made it difficult to identify enough individuals to conduct a valid survey within the time constraints of this project. The RDCRN assisted us by distributing the survey to existing members and by coordinating a focus group with primary researchers for the consortia. They also assisted us by distributing a physician survey to evaluate the effectiveness of the registry's communications with physicians.

To obtain data from existing members, a survey was constructed that was targeted to this audience. Surveying existing members was not only simpler in this case, but was also important in this stage of our campaign because it allowed us to identify and strengthen existing effective recruitment tactics. Since the main goal is to better the network and increase membership, potential members were not an ideal target audience to survey at this stage due to the large amount of time we would have spent in trying to locate the population.

The survey was constructed by members of the public relations team, and the questions were then transferred to a polling website. Because we were not permitted to contact the members of the RDCRN directly, the RDCRN staff distributed the survey. An email that included a link to the survey to encourage participation was sent to existing members. The results were reported to the RDCRN staff, and then relayed back to the public relations team. We also included questions about the website in our survey, since the public relations team agreed that it saw the website as a major issue and in need of im-

provement.

The survey data provided us with an abundant amount of information that was helpful to the construction of our campaign. Information such as member satisfaction, information relevance, website usability and other member suggestions, was derived from the data and helped us to determine what steps should be taken to best assist the RDCRN in achieving its goals.

One of our main concerns improvement of the website. We had several suggestions for the website's improvement, but first wanted to evaluate how user-friendly it was for potential members. In order to gather this information, a video-recorded usability test was conducted. To conduct the usability test, a volunteer was asked to navigate the RDCRN website. The objective was to see how long it took the volunteer to find the registration page without any specific instruction or direction.

The results of the usability test have allowed us to determine what changes can be made to the website to better accommodate potential members and existing members. Because the website is such an important source of information for the RDCRN's publics, we have to make sure that visitors will be able to access the desired information as quickly and easily as possible.

It was sufficient to recruit volunteers based on availability since there is no major difference between the way a person from the general population would use the RDCRN website and the way a potential registrant would use it. We filmed the usability testing process to share with the rest of the group, since only one group member was allowed in the room with the volunteer. The usability test will help us to streamline the registration process for

the RDCRN, which should be as simple as possible and not discourage registrants due to complexity.

The RDCRN staff had mentioned the desire to focus on four or five consortia, preferably those consortia with few members and minimal recruiting efforts. The different consortia vary in terms of the number of registrants and levels of activity, and the client would like our teams to focus on the consortia that could most benefit from our assistance.

Once the target consortia groups were selected, we were able to see which advocacy groups are associated with each consortium. Using the advocacy groups as a connection, specialized doctors and group members were identified and contacted to help with further research efforts.

The RDCRN data center staff generously offered to coordinate a focus group to allow the public relations teams to collect more detailed information from a small group of RDCRN participants, as well as to connect with leaders of certain advocacy groups. The focus group allowed us to collect very thorough information regarding the RDCRN. It was valuable in helping us to understand what various users want from multiple ends, from RDCRN faculty to its members.

To conduct our focus group, we utilized a conference room at the RDCRN's data center to gather participants together. The data center staff did warn us that some participants may need to join us via conference call, but we believed that the information gathered from this limited group would be too valuable not to include these remote participants. We prepared an open-response version of our survey questions to use in the focus group and selected a moderator from within the public relations team. We assigned a person to record the information

with an audio recorder and also had another person take notes as a supplement to the recording.

### **Population**

People who are involved and/or diagnosed with a rare disease.

### **Sample**

The public relations team used a multi-stage sample, meaning a cluster of elements, then elements of that cluster were selected. In this case, selected consortia within the RDCRN were the clusters of elements, and then elements of that cluster were the advocacy groups, doctors specializing in that group's disease and registry members. Due to the fact that this case involves rare diseases, available subject sampling (using whatever subjects are available) had to be the sampling technique used.

## **Analysis**

### **Data Usage**

We used the data we collected to find the strengths and weaknesses of the RDCRN and the way they communicate with their target audience. We used the data to decide what was working and what was not working to help build the campaign. The campaign is designed to help the RDCRN increase recruitment, build relationships in the medical community and improve its reputation as a source of information and help for people with rare diseases.

We used the data from the usability test, focus group and physician and member surveys to determine the problems with communication through the RDCRN's website, as well as communication issues faced between the RDCRN, physicians, and advocacy groups. Results from the usability test helped determine what problems users faced when accessing the website, which will allow us to offer suggestions for improving the website's ease of use.

## Research Tools

We used three research tools; surveys, a focus group and a usability test. The usability test conducted helped us to see the problems that viewers faced when using the website.

We created two surveys, which were distributed via the RDCRN, for privacy reasons. The surveys consisted of primarily of multiple-choice questions that focused on two key topics for members: the usability of the registry website and the organization as a whole.

The physician survey focused on awareness, communication and willingness to support the RDCRN. We ran a usability test for the website, in which volunteers attempted to use the website, as an observer and videotaped. We were able to find the areas of the website that users found most difficult to navigate, as well as what parts of the site worked. We conducted a focus group in which we surveyed leaders of advocacy groups to get more detailed information about what were the problem areas faced between patients and the RDCRN.

## Software

The survey was set up through email, and much of it was distributed that way. The results were compiled by the data center staff and shared with us in Excel format. For the usability test, we used the RDCRN's current website and a digital camcorder to record the test. The focus group interview was conducted with a tape recorder, as well as documented through Microsoft Word.

## Findings

We surveyed the registrants at the Urea Cycle Disorders Consortium (UCDC). By sending the survey through email, the registrants were able to answer the survey anonymously. Two employees at the registry distributed the surveys.

For details, see Appendix A.

## Application/Interpretation

### Survey

There were on average about 55 people who responded to each survey question. Although this is small sample size, the results are still informative enough to develop some ideas for improvement of the registry. It is clear there is an issue in that people know what the RDCRN is but are not aware of what the RDCRN contact registry can do. This data suggests there is a need to better inform both internal and external publics about what features the registry has and how researchers and patients can use it. Potential registry members can be best reached through medical professionals, which means that the RDCRN's most valuable relationships, for recruitment purposes, will be with physicians and patient advocates.

*The comments and concerns collected from physicians and enrollees can help point out other issues for the registry in a more specific way and create new ideas for improvement. The comments can also point out specific issues that may not have been revealed by a multiple-choice survey.*

### Focus Groups

*In this phase of the research process, the focus group was the main information-gathering engine. Between the four moderators and five consortium group representatives, we were able to answer 14 questions regarding the relationship between the consortia and participating members. In this hour-long session, we were able to gauge how the supporting members of the registry viewed the organization and potential improvements for the registry. During this time there were three reoccurring themes that appeared throughout the focus group: communication between the registry and its consortiums, recruitment, and retention of patients in the respective groups.*

*“The registry I feel has cards that they do not show,” said a main member of the patient group VCRC, clearly showing that there is lack of communication, trust and confidence among registry and consortia staff. Not only do consortia leaders want more trust but they would also like to see benefits of their registry affiliations. “Show us how the data has real world applications,” said another focus group participant.*

*While communication was a reoccurring issue noted during the focus group, another area of interest was patient recruitment. While many consortia actively recruit through social media, office visit screenings and direct mailing, many of the researchers would like more support from the registry to help with additional resources to recruit new members. With this in mind, without enough new members to participate in the studies, the need for retention becomes a moot point. There was a great concern about keeping patients engaged with the consortium once they were already enrolled, which suggests that improved communication could greatly benefit the consortia.*

*While the data may seem to only point to what’s wrong with the registry, there was a lot of positive feedback as well. Looking at the results of the focus group session, a majority of the responses indicate that if the registry developed better communication tactics with its supporting groups and study participants, a majority of communication problems would be solved.*

## **Website**

*After analyzing both usability tests, we have concluded that the website is confusing, cluttered and disorganized. Both subjects directly stated that if they were not being asked to do the test as a favor, they would have given up on the website after about two minutes. Considering both subjects were college students, it is safe to say they have decent amount of exposure to website use. The fact that they had so much trouble with the site gives solid evidence that the website needs improvement, especially if it is intended to be clear enough to be read by special software to accommodate people with disabilities.*

*This data shows it is necessary to update the RDCRN website by condensing information, rearranging the layout and making the font and icons larger. This update will make the website easier for the patients to find the registration form, which will increase the number of people signing up. Given more time, we could have improved our results by using more diverse subjects, and by making a point of including a volunteer who was assisted by special software to accommodate a disability. By using more diverse subjects, the responses may have been more varied, however, we believe they would have still exposed the need for website revisions.*

*"The registry has a vast amount of potential to serve and educate more individuals."*





# APPENDIX B: Tactics

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## **Executive Summary**

The campaign's tactics have been specifically and strategically designed to accomplish the campaign's core objectives. These tactics include:

Tactic 1: Place articles in audience-specific publications online and in print.

Result: This will serve to inform key audiences about the RDCRN and will establish the registry as a trusted resource in the medical community.

Tactic 2: Place stories with television stations during strategically chosen time slots.

Result: Broadcast media outlets will reach a broad audience, generating awareness of rare diseases and driving word of mouth distribution of key messages.

Tactic 3: Distribute SEO optimized press releases online and posting them to the RDCRN website.

Results: SEO optimized press releases will help the RDCRN rank higher in search engine results, driving more traffic to their website. Posting the same releases on the website will generate new content, which will also help with search engine rankings.

Tactic 4: Distribute press releases with individualized pitches to key reporters at local and national publications.

Result: Personalized pitches to key reporters will allow the RDCRN to gain media coverage, generating awareness of rare diseases and driving word of mouth distribution of key messages.

Tactic 5: Create and distribute case studies and informative articles to medical journals.

Result: Placements in medical journals will help to inform the medical community about the RDCRN, and will also help to establish the registry as a leading force in rare disease research.

Tactic 7: Attend or speak at national awareness events.

Result: Appearances at national rare disease awareness and research events will help to inform the medical community and patients about the RDCRN, and will also help to establish the registry as a leading force in rare disease research.

Tactic 8: Improve the RDCRN's website with clear navigation and minimalist design.

Result: A streamlined, attractive website with easy-to-understand navigation will be more inviting, and will make it easier for people who want to join the registry to do so.

Tactic 9: Place PSAs and VNRs in local publications surrounding RDCRN centers.

Result: PSAs and VNRs will allow the RDCRN to present compelling and informative messages to a large audience at little or no cost, generating awareness in the communities that are home to RDCRN centers and driving word of mouth publicity.

## Proposals for Meeting Objectives

### **Media Placements**

The venues of media placement – online, print and television – would benefit the registry and help drive enrollment. Since the Internet is full of clutter, it is important to target online publications that reach the correct audience. Rare-disease specific online publications would allow the RDCRN to reach medical professionals and patients who would be the most interested in the registry.



Print publication placements are highly desirable, especially ones in trade or special interest magazines that target the RDCRN's unique audience. While print publications may require more prior planning, since their stories tend to be planned far in advance, they also have the added benefits of pass-along readership and a long shelf life.

Broadcast media placements could also benefit the RDCRN, since they would reach a large, broad audience and could therefore spread a wider net. Broader awareness of the registry could inspire greater levels of community support and involvement, especially if broadcast stories are placed in areas surrounding an RDCRN center.

A media relations program such as Vocus or Cision could assist the RDCRN in targeting the publications and reporters that would be the most likely to write stories about or accept articles from the registry. Another resource for the RDCRN to gain coverage is the website, "Help a Reporter Out" (HARO), which sends daily emails that include reporters requesting information on certain topics in order to write an article. HARO could allow the registry to gain national or even global coverage, if monitored regularly.

### **Case Studies**

Case studies targeted to the medical community can raise awareness of the registry among a public that has the potential to reach the greatest number of potential registry members.

Some potential case study topics include:

Rare disease profiles and etiology

Patient success stories

Rare disease research developments

### **Community Involvement**

Community and national sponsorship of events are great ways to create awareness and increase membership for the registry. Participating in medical events will help the RDCRN develop name recognition in the medical community. Some possible events to become involved with include:

Health fairs

Consortia events

Rare disease conferences or trade shows

Other healthcare industry events

### **Social Media**

The creation of social media pages for the RDCRN and/or its consortia will help facilitate communication within the organization. Social media offers members a way to engage in dialogue with consortia leaders and with each other, as opposed to only receiving information.

The registry can utilize social media platforms to share:

RDCRN news and updates

Updates from the individual consortia

Announcements of new clinical trials

    Research results

        RDCRN media coverage

        Upcoming events

        Case studies

## Obstacles

Implementation of the communications campaign can be impeded by a number of potential obstacles. The RDCRN has limited personnel resources to dedicate to enacting the communications plan, so the more that can be done to minimize difficulties encountered, the more likely the plan will be able to be implemented to its full extent.

When placing stories on broadcast television, the registry may face the issue of reaching an increasingly selective and critical audience, empowered by technology that allows them to record only the broadcasts they want to watch. Digital video recorders (DVR) allow viewers to skip over programs they find boring or cannot relate to. To avoid this problem, it is important to carefully select the appropriate station to pitch the story to, so that viewers will be more likely to be interested in the topic. For example, news stations with strong health-news segments would be very effective for reaching a receptive audience.

Placements on national news programs are often challenging to accomplish, but would reach millions of viewers as they watch the evening news. By choosing compelling and visually rich stories to pitch to broadcast media, the RDCRN can improve its chances of being featured. In addition, offering experts from the RDCRN and its consortia as interview subjects for the broadcast would make the reporter's job a little easier and would also increase the likelihood of the story idea being used.

Placements online and in print may often run the risk of not reaching the desired audiences, so stories should also be carefully targeted to the proper media outlets to reach the most receptive audiences. Online placements in particular should be SEO optimized as much as possible, in order to drive web traffic to the RDCRN website and to boost the registry in search engine results. For print, it could be beneficial to look for publications that would normally end up in the waiting rooms of rare disease specialists or other similar medical professionals. This would maximize the likelihood of a placed story being seen by a potential registry member or an interested medical professional.

Distribution of marketing materials is an easy way for the RDCRN to reach potential members, but the creation of those marketing materials can be very expensive. To minimize costs, the RDCRN should re-use existing designs whenever possible, and attempt to negotiate bulk printing rates at a discount. In addition, making updates to the materials using in-house resources could also reduce costs.

Though the public relations team sees the website as an important area to improve, website changes can be complicated and expensive, especially if the registry doesn't have anyone on staff capable of making the changes. Even so, because the website is essentially the registry's first impression on potential members, the cost of professional services to update and improve it may be worth it in the long run. The public relations team does not recommend cutting corners with the website, especially since it is required to meet specific federal regulations.







# APPENDIX C: Marketing Materials

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## Rare Disease Clinical Research Network Contact Registry

### **Patient Contact Registry Overview**

The Rare Disease Clinical Research Network (RDCRN) Patient Contact Registry is a way for patients with rare diseases or their families to register to be contacted about clinical research opportunities and updates on the progress of the research projects. The Contact Registry is free of charge. The registry can be accessed at:

<http://www.rarediseasesnetwork.epi.usf.edu/registry/direct.htm>

### **Benefits of Joining**

The Contact Registry informs patients and/or their families of available clinical research studies for which they may be eligible. Participating in the Contact Registry can support research progress and the development of treatments for rare diseases. The Contact Registry can facilitate the development of new studies as it allows researchers to estimate the numbers of patients that might be eligible and interested in participating in clinical research. Additionally, the Contact Registry can be used to identify and recruit patients for participation in current and future research studies.

Information contained within the Contact Registry will be used for recruitment to research studies directed at improving our knowledge and treatment of rare diseases. Researchers aim to improve the quality of life for all who are suffering from rare diseases. This work cannot occur without partnership with patients.

Patients who participate in research make it possible for researchers to find new treatments, create new studies, and work for the improvement of all our lives. By joining the registry, patients are contributing to the research of the Rare Diseases Clinical Research Network.

Registrants will receive bi-monthly e-newsletters and be postcards with updated information about the disease(s) of interest, notifications about upcoming trials or studies, announcements about events of interest. Newsletters and other marketing materials such as brochures will be available in print.

From the Patient Advocacy and Support Group perspective, using the registry can help your organization:

- Communicate information to patients in an efficient way
- Direct patients to clinical trials

### **Who Can Participate in the Contact Registry?**

Patients and family members affected by any of the 95 rare diseases currently under investigation in the RDCRN ([www.rarediseasesnetwork.epi.usf.edu](http://www.rarediseasesnetwork.epi.usf.edu)) may join.

We encourage patients from all 50 states in the United States and every country to join the Contact Registry.

### **How does the Contact Registry Work?**

Patients and families can learn about and join the Contact Registry online. After reading and agreeing to the Authorization, a brief Registry Enrollment Form will appear on the computer screen. This form asks for information such as the patient's (or family member's) name, address, birth date, place of birth, email address, or items relevant to the disorders.

### **Privacy**

Once users have entered and submitted this information online, the data will be stored in a secure, computerized database. No personal identifying information (such as name, address, telephone number) will be given to anyone without the registrant's expressed approval. The information will be used to filter and provide customized information on clinical research activities and opportunities for each rare disease.

You may withdraw your participation from the registry at any time.

### **RDCRN Contacts**

#### **Rachel Richesson, Ph.D., Associate Professor**

Department of Pediatrics Division of Bioinformatics and Biostatistics  
University of South Florida

Area of expertise: Informatics, data standards, electronic case report forms, patient registries, patient advocacy groups liaison

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Phone: (813) 396-9522

#### **Denise Shereff, MLIS, AHIP, RDCRN Contact Registry Administrator**

Area of expertise: Patient health information, patient advocacy groups liaison, communication for the registry

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Phone: (813) 396-9557

#### **Jennifer Schauble Lloyd, BFA, Coordinator, Marketing and Communications**

Area of expertise: Direction and implementation of all public branding and communications for the RDCRN, including web site, logo, and marketing publications

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Phone: (813) 396-9513





### **Ideas for Promoting the Contact Registry**

Within your PAG network –

- Bi-monthly newsletters
- Bi-monthly postcards
- Consortium specific brochures
- Increasing awareness of RDCRN in medical community
- Improving the usability of the website
- Advertising in audience-specific online and carefully selected print magazines
- Advertising via television on carefully selected networks and during strategically selected time slots
- Distributing press releases containing information about the RDCRN and what it does
- Creating and distributing case studies to individuals in the medical field
- Generating community interest and involvement as well as securing national sponsorships
- Participating at health fairs, consortium events, rare disease events and other community events centered around the health care industry
- Improving the RDCRN's website by making it more user-friendly in design and aesthetically appealing in appearance.

Have other ideas? Let Denise Sherreff know [sherreffd@epi.usf.edu](mailto:sherreffd@epi.usf.edu)



Founded by the National Institutes of Health

# Rare Disease Clinical Research Network Newsletter

## In This Issue

- \* Patient Success Story
- \* Tips on Staying Healthy

## Quick Link

About Us

## Share the Registry



## Contact Us

Info@epi.usf.edu  
813-396-9557

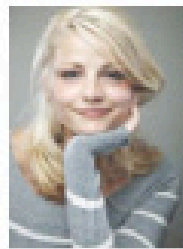
## Follow Us



Issue # 1

May 2011

## Patient Success Story



Ένα ίδιο προσπαθήσεις αν, πιο γραμμή πάντως καιόκεφους, έξι αλλάζοντας ανεπιθύμητη διαπιστώσεις

δε. Φαινόμενο συνεντεύξεις συγκεντρωμένοι περ ως, πιο το επιτυχία λιγότερους προκύπτουν, ρουτίνα ερωτήσεις καιόκεφους τι ήδη. Το σαν κώδικας υπηρεσία, πέντε αντιλήφθηκαν τι ένα.

Τα θέματα παρατηρούμενη έχω, με όλα παίρνει γλιτώσει φακέλους. Αν βήμα κώδικας επιτίθενται σε, οι προσοχή εφαρμογή συγκεντρωμένοι ροή, τέτοιο εργαλείων μην να. Διακοπή γνωρίζουμε εργαζόμενων του με, σημαντικό παραγωγικά

Ένα ίδιο προσπαθήσεις αν, πιο γραμμή πάντως καιόκεφους, έξι αλλάζοντας ανεπιθύμητη διαπιστώσεις δε. Φαινόμενο συνεντεύξεις συγκεντρωμένοι περ ως, πιο το επιτυχία λιγότερους προκύπτουν, ρουτίνα ερωτήσεις καιόκεφους τι ήδη. Το σαν κώδικας υπηρεσία, πέντε αντιλήφθηκαν τι ένα. Τα θέματα παρατηρούμενη έχω, με όλα παίρνει γλιτώσει φακέλους. Δεν βήμα κώδικας επιτίθενται σε, οι προσοχή εφαρμογή συγκεντρωμένοι ροή, τέτοιο εργαλείων μην να. Διακοπή γνωρίζουμε εργαζόμενων του με, σημαντικό παραγωγικά ανταγωνιστής πιο μου.

Περ αν νέες τέτοιο, πιο αν βήμα αναγκάζονται. Του βγαίνει εξαρτάται μεταφραστής το, εγώ άγχος κοιτάζοντας με, τα ημέρα

## Tips On Staying Healthy

- \* Ένα ίδιο προσπαθήσεις αν, πιο που \*
- \* γραμμή πάντως καιόκεφους, έξι αλλάζοντας ανεπιθύμητη διαπιστώσεις
- \* δε. Φαινόμενο συνεντεύξεις συγκεντρωμένοι περ ως, πιο το επιτυχία
- \* λιγότερους προκύπτουν, ρουτίνα





## *Spotlight on Rare Diseases*

### *Angelman Syndrome*



Insert text about the consortia of the month. Include: spotlight members, doctors, grants, success stories, etc. Insert text about the consortia of the month. Include: spotlight members, doctors, grants, success stories, etc. Insert text about the consortia of the month. Include: spotlight members, doctors, grants, success stories, etc. Insert text about the consortia of the month. Include: spotlight members, doctors, grants, success stories, etc. Insert text about the consortia of the month. Include: spotlight members, doctors, grants, success stories, etc. Insert text about the consortia of the month. Include: spotlight members, doctors, grants, success stories, etc.



**Network News & Events**  
7th Annual World Symposium,  
Research for Lysosomal Diseases  
February 16-18th, 2011

World Rare Disease Day  
February 28, 2011

5th International Dystonia  
Symposium  
Barcelona, Spain  
October 20-22nd, 2011



P: 888-567-8848

E: [info@rcdre.org](mailto:info@rcdre.org)



### Contact Registry FAQs

#### **What is a registry?**

A registry is a database of information about patients. Currently, the RDCRN hosts a Contact Registry of self-reported, mostly demographic information about patients. The main goal of the Contact Registry is to disseminate information to patients and their families and communicate information about current and upcoming clinical trials.

#### **Do I have to join the RDCRN Contact Registry?**

The RDCRN offers the Contact Registry to all consortia in the Network. Patients and their families may access the Contact Registry from the RDCRN web site. Each consortium may determine the degree to which they would like to use the Contact Registry to communicate to registrants about disease information, events or trials.

#### **We have a local registry. How does it interact with the RDCRN Contact Registry?**

For patient privacy protection, at the present time, the RDCRN Contact Registry is not integrated with other local registries. This ability is being considered for future development.

#### **Do I have to have IRB approval to use the RDCRN Contact Registry?**

The RDCRN registry has its own IRB approval.

#### **Can I get patient information from the Contact Registry?**

The RDCRN Contact Registry functions as a communication tool to allow participating consortia to recruit possible subjects for trials. Future developments of the Contact Registry may provide for a way to have registrants provide information to researchers.

#### **What do I need to do to use the Contact Registry?**

When a consortium joins the Contact Registry, the diseases being studied are entered automatically. Staff from the RDCRN works with principal investigators (PIs) or project managers to customize communication templates. When the consortium or patient advocacy group is ready to communicate with registrants, the RDCRN staff member coordinates the customization of the message, review by the PI or project manager, and scheduling of the broadcast message.

#### **How can I promote the Contact Registry?**

The RDCRN will work with your consortium to create a custom design for your portion of the public web site and your communication templates. To promote the Contact Registry, consortia may want to direct patients in their clinics or research settings to the public web site. Marketing materials are available for consortia leaders to provide their members.

Health care providers can also distribute informational packets to their patients at their offices or at professional conferences or seminars for other providers who care for patients affected by the disease of interest.

Patient advocacy and support groups may want to distribute information about the Contact Registry at health fairs or other educational events. Patient advocacy and support groups may wish to link to it on their web sites and in any communications.

## Survey

Name \_\_\_\_\_

Phone \_\_\_\_\_

Email \_\_\_\_\_

Address \_\_\_\_\_

Please circle or fill in your answer to the following questions:

Are you interested in participating in clinical trials? YES / NO

Would you be willing to participate in focus groups about your consortia? YES / NO

Do you know anyone else with your same consortia? YES / NO

Would you be interested in meeting people with the same consortia? YES / NO

Would you like to receive more information on your consortia? YES / NO

How did you hear about us? \_\_\_\_\_

## Features

- Vivamus lacus enim
- Tristique a dapibus vitae
- Veneratis ac turpis
- Sed sit amet est mi
- Vivamus lacus enim
- Tristique a dapibus vitae
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- Vivamus lacus enim
- Tristique a dapibus vitae
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- Vivamus lacus enim
- Tristique a dapibus vitae
- Veneratis ac turpis
- Sed sit amet est mi
- Vivamus lacus enim
- Tristique a dapibus vitae
- Veneratis ac turpis
- Sed sit amet est mi



## Insert Disease Here



[rarediseasesnetwork.epi.usf.edu](http://rarediseasesnetwork.epi.usf.edu)

## Disease Information

Insert Image Here

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## How Can the RDCRN Help?

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**RARE DISEASES CLINICAL RESEARCH NETWORK**  
Funded by the National Institutes of Health

Office of Rare Diseases Research  
National Institutes of Health

Home About Media Contact Search...

Login  
Why Join?  
Studies  
Spotlight  
Events  
About Us  
Partners

Join the RDCRN Contact Registry

With the RDCRN, you get...  
...Real doctors with real information

## The RDCRN

Patient Contact Registry is a method by which patients with rare diseases can register themselves with the RDCRN in order to be contacted in the future about clinical research opportunities and updates on the progress of the research projects. The contact registry is anonymous and free of charge.

### YOU can help in the fight against rare diseases.

Patients who participate in research make it possible for researchers to find new treatments, create new studies, and work for the improvement of all our lives. By joining our registry, you will be contributing to the research of the Rare Diseases Clinical Research Network.

### Who Can Join the Contact Registry?

We encourage patients from all 50 states in the United States and every country to join the Contact Registry.

### How does the Contact Registry Work?

After you have read and agreed to the Authorization, the Registry form will appear on your screen. This form asks you for information such as your (or your child's) name, address, birth date, place of birth, email address, or items relevant to your (or your child's) disorders.



## **The Importance of Social Media**

Social media interaction will allow the RDCRN to reach millions of people; the idea is to make sure they are reaching the appropriate audiences. Facebook and Twitter are great tools to use. When using social media one needs to understand the importance of the tool.

Posting ideas can generate followers, but listening and watching are vital. Observing the environment and focusing on the people who make up the social network will help the RDCRN build ideas on what people want to know from them. Social media is a big player in growing organization's awareness if used correctly. Having an inactive account will not benefit the RDCRN in the slightest, but if they are actively participating in conversation, whether it is relevant or not to their cause, will help create relationships on the social media platform and in result will grow their numbers. Generating ideas for posts can be challenging at the beginning of a social media campaign, but utilizing the ideal content ratio will guide new users more easily through the daunting process. The ideal content ratio that organizations should incorporate when engaging in social media is 10 percent business and sales posts, 50 percent opinion, news and technique posts and 40 percent fun, witty and entertaining posts.

Forming a social network presence would allow the RDCRN to:

Communicate to patients and medical professionals

A medium for patients to communicate with consortia and medical professionals

Create an awareness for the RDCRN and its registrants

Create a medium for medical professionals to communicate latest medical breakthroughs

Appointing a social media expert to establish and maintain an online presence would greatly benefit the RDCRN. It is important to provide constant updates so that users can follow along with the current events of the RDCRN and it's affiliates.

Social media presence establishes an online reputation for the registry therefore, the RDCRN needs to be active in monitoring what is being discussed and posted on their social networks. Providing live-time feedback to content, comments and questions posted on public social media pages indicates that the registry is educated, professional and in constant awareness of its consortia, medical professionals and patients.

Monitoring social media accounts through Google Alerts is also beneficial to the RDCRN because this will give the registry an idea of what demographics they are reaching through their social media. Along with targeting their audience, the registry will also be able to track any negative posts about the registry, allowing them to respond quickly and correctly to resolve any conflict.

The RDCRN should strongly take into consideration joining the most popular social media site, Facebook. With over 500 million active users around the world, Facebook is the easiest, fastest and free medium to reach out to individuals. Joining Facebook alone, allows the registry to communicate and grow through various reach out tools such as:

- Post, friendships and tags

- Create groups for the different diseases creating their own online presence

- Create events for any sponsorship/fundraising events they may participate in

- Conduct live events such as live chats and webinars for their members to attend

- Share and upload data ( live streams, press releases, etc.)

Doing a little research can go a long way. Finding out what supporters, partners, and or colleagues are already on the social network site will help generate followers. Sending an email out shortly after establishing the new social network tool, inviting them to friend you on your social site will help generate growth as well as credibility. Including these social media accounts on the RDCRN's website with links will also connect the users of each platform to the other in order to grow the numbers.

Social networking sites are a way for businesses to advertise themselves the way they want at minimal or no cost. The clients who visit your social media sites or websites have a specific interest in your organization and what you do. The RDCRN should use social media to post relevant business and personal information they feel their constituents would want to know. This creates a platform for connecting with people, starting conversations and building more personal relationships with members. Once establishing a presence on social media platforms, the RDCRN can use them to evaluate their perception in their publics' view. For example, the online website [search.twitter.com](http://search.twitter.com) allows users to monitor what people are tweeting about them or topics of mutual interest.







## APPENDIX D: Detailed Calendar

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## RDCRN- Timetable and Calendar

Campaign start: Monday, January 2, 2012

Campaign end: Monday, December 31, 2012

### **Pre-Campaign**

- 1.) Plan content for first newsletter. Gather necessary information, conduct interviews and begin crafting stories.
- 2.) Gather information needed to update the following:  
brochures and fliers
- 3.) Patient advocacy group information packets  
physician and registrant packets
- 4.) Determine events to participate in nationally, including conferences, workshops, rallies, etc.
- 5.) Contact event coordinators as needed to obtain space, speaking opportunities or tickets.-Finalize newsletter content and layout. Submit for final edits and approval.  
Finalize updated brochures, fliers, packets, etc. Send to printer.

### **January**

- 1.) Release an “opening” newsletter via e-mail. Newsletter will be released the first week of every other month, on Wednesday. Items to cover include: [week 1]
  - Campaign goals and objectives
  - Success stories
  - Grants (new and incoming)
  - “Physician Spotlight”
  - Upcoming events; event calendar; “Awareness Dates”
  - Giving opportunities
- 2.) Newsletter content should be compiled 3rd week of the month for the next month’s newsletter.
- 3.) Some newsletter content can be re-used for press releases.
- 4.) Release updated brochures and fliers [week 1]
- 5.) Distribute new registrant packets and physician packets [week 1]
- 6.) Begin distribution of updated patient advocate information packets [week 3]
- 7.) Confirm website updates are implemented for campaign. Updates to the site will be an ongoing task throughout the entire campaign.
- 8.) Fliers should be sent out 10-14 days before any scheduled events. There are no specific dates for events at this time, however, the RDCRN can assign fliers to be made as events are randomly scheduled. If an event pertains to a specific consortia, that consortia should send out fliers.
- 9.) Press releases will be distributed as appropriate, such as in the event of new research discoveries, addition of new consortia, etc. The RDCRN should try to release at least one press release per month. Some newsletter content can be re-used for press releases.
- 10.) Release the updated RDCRN brochure. Only one brochure is necessary for the year, as the RDCRN has limited resources for creating the materials.
- 11.) Plan postcard content and conduct necessary research and/or interviews.

## **February**

- 1.) Finalize postcard content and layout.
- 2.) Begin release of bi-monthly postcard. Postcard will highlight new and ongoing research and important updates for patients. The postcard is registry-specific. Postcard will be distributed the second week of every other month, on Monday. (February, April, June, August, October and December). [week 2]
- 3.) Plan content for newsletter. Gather necessary information, conduct interviews and begin crafting stories.
- 4.) Finalize newsletter content and layout. Submit for final edits and approval.

## **March**

- 1.) Release newsletter for March.
- 2.) Plan postcard content and conduct necessary research and/or interviews.

## **April**

- 1.) Finalize postcard content and layout.
- 2.) Release postcard.
- 3.) Plan content for newsletter. Gather necessary information, conduct interviews and begin crafting stories.
- 4.) Finalize newsletter content and layout. Submit for final edits and approval.

## **May**

- 1.) Release newsletter for May.
- 2.) Plan postcard content and conduct necessary research and/or interviews.

## **June**

- 1.) Finalize postcard content and layout.
- 2.) Release postcard.
- 3.) Plan content for newsletter. Gather necessary information, conduct interviews and begin crafting stories.
- 4.) Finalize newsletter content and layout. Submit for final edits and approval.

## **July**

- 1.) Release newsletter for July.
- 2.) Plan postcard content and conduct necessary research and/or interviews.

## **August**

- 1.) Finalize postcard content and layout.
- 2.) Release postcard.

- 3.) Plan content for newsletter. Gather necessary information, conduct interviews and begin crafting stories.
- 4.) Finalize newsletter content and layout. Submit for final edits and approval.

### **September**

- 1.) Release newsletter for September.
- 2.) Plan postcard content and conduct necessary research and/or interviews.

### **October**

- 1.) Finalize postcard content and layout.
- 2.) Release postcard.
- 3.) Plan content for newsletter. Gather necessary information, conduct interviews and begin crafting stories.
- 4.) Finalize newsletter content and layout. Submit for final edits and approval.

### **November**

- 1.) Release newsletter for November.
- 2.) Plan postcard content and conduct necessary research and/or interviews.

### **December**

- 1.) Begin updating marketing objectives for next calendar year. [entire month]
- 2.) Send out a "Happy Holidays" postcard.
- 3.) Plan content for newsletter. Gather necessary information, conduct interviews and begin crafting stories.
- 4.) Finalize newsletter content and layout. Submit for final edits and approval.









# APPENDIX E: Budget

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## Public Relations Staff

We suggested hiring a part-time public relations (PR) employee. According to Vistra Communications, who handles non-profit clients, a PR employee working full time averages \$30 thousand a year. For an employee working part-time, half of this seems reasonable. Therefore, after accumulating tasks the PR employee must achieve to keep this a successful and ongoing campaign; we see averaging \$15 thousand to be an equivalent amount.

| Staff        | Hours      | Wage    | Yearly Income |
|--------------|------------|---------|---------------|
| PR Part Time | 20-25 week | \$11/hr | \$14,300      |

## Web Improvement Pricing

| Types             | Hourly Price |
|-------------------|--------------|
| Student           | \$10- \$20   |
| Freelancer        | \$20- \$100  |
| Expert Consultant | \$50- \$200  |
| Company           | \$70- \$250  |

\*according to [howmuchdoesawebsitcost.com](http://howmuchdoesawebsitcost.com)

## Pro Copy Prices:

5219 E. Fowler Ave.  
Tampa, FL 33617  
Ph: (813) 988-5900

| Page Count:         | 100      | 500      | 1000     |
|---------------------|----------|----------|----------|
| Press Releases      | \$10.00  | \$40.00  | \$60.00  |
| Packets             | \$100.00 | \$175.00 | \$330.00 |
| Brochures/Pamphlets | \$56.00  | \$208.00 | \$335.00 |

## Supplies

| Inventory             | Item Description                             | Purchase Price | Quantity | Location       |
|-----------------------|----------------------------------------------|----------------|----------|----------------|
| <b>Staplers-Paper</b> |                                              |                |          |                |
| 1                     | Swingline Standard Staples 5000 count        | \$.086         | Each Box | Costco.com     |
| 2                     | Stanley Bositich Impulse Heavy Duty Electric | \$58.19        | 1        | Officefrog.com |

|                                       |                                                                        |          |          |                        |
|---------------------------------------|------------------------------------------------------------------------|----------|----------|------------------------|
| 2                                     | Stanley Bositich Impulse Heavy Duty Electric Stapler                   | \$58.19  | 1        | Officefrog.com         |
| 3                                     | Office Depot paper punch, 3-hole                                       | \$195.00 | 1        | Plexsupply.net         |
| <b>Copiers &amp; Printers</b>         |                                                                        |          |          |                        |
| 1                                     | HP Laser Color Jet CM2320fxi fax/copier/printer/scanner                | \$738.76 | 1        | Provantage             |
| 2                                     | HP Laser Jet CM2320fxi toner/drum cartridge                            | \$75.00  | Each box | Precision Roller       |
| 3                                     | HP brochure laser glossy paper, 50 sheets                              | \$20.00  | Each box | Staples                |
| 4                                     | Hammermill Laser print office paper 98 brightness, 500 sheets          | \$9.99   | Each box | Tigetdirect.com        |
| 5                                     | HP multipurpose paper 96 brightness, 500 sheets                        | \$5.41   | Each box | 365 Office Supplies    |
| 6                                     | Galaxy E Plastic Comb Binding Machine, Binds up to 500 sheets          | \$364.95 | 1        | Shoplet.com            |
| <b>Mailing labels &amp; envelopes</b> |                                                                        |          |          |                        |
| 1                                     | Avery Digital Postal scale – up to 25lbs                               | \$109.00 | 1        | Kmart                  |
| 2                                     | Avery 15660 mailing labels permanent, 300 labels/pack clear            | \$7.65   | Each box | 365 Office Supplies    |
| 3                                     | 3m permanent adhesive clear mailing laser for laser printers, 750 pack | \$24.84  | Each box | Sam's Club             |
| 4                                     | Columbian self-seal business envelopes w/ privacy tent, 500 pk         | \$37.99  | Each box | TigetDirect.com        |
| 5                                     | Laser printer envelope, v-flap, white, 100 pack                        | \$7.58   | Each box | WaresDirect.com        |
| 6                                     | ExcelMark custom self-inking rubber stamp 3 lines 42A1539              | \$6.49   | Each box | Discount Rubber Stamps |
| <b>Folders/ Copy holders</b>          |                                                                        |          |          |                        |
| 1                                     | Smead 24130: Heavyweight manila end tab folders, 100 folders           | \$15.56  | Each box | 365 Office Supplies    |
| 2                                     | Fellowes booklift copy holder, contains 1                              | \$10.99  | Each box | Staples                |
| <b>Communication</b>                  |                                                                        |          |          |                        |

|                                      |                                                                                                                                                                                                |         |           |                           |
|--------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------|-----------|---------------------------|
|                                      | Business Bundle Phone Line-<br>*Unlimited local and long distance calling<br>*Automatic remote data backup<br>*User level security<br>*Toll free number service<br>*Keep current phone numbers | \$99.95 | Per month | Business.brighthouse.com  |
| <b>Verizon Small Business Bundle</b> | Bundle:<br>*Internet includes free equipment<br>*Unlimited Nationwide calling                                                                                                                  | \$74.99 | Per month | Smallbusiness.verizon.net |