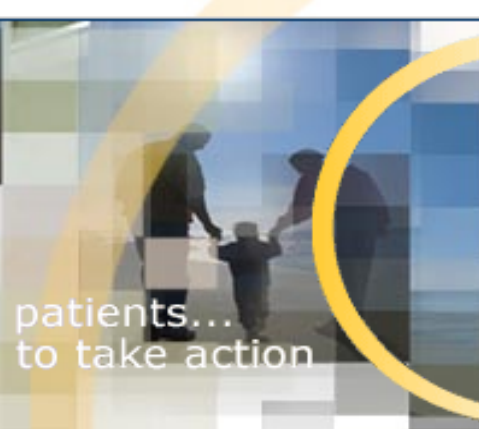
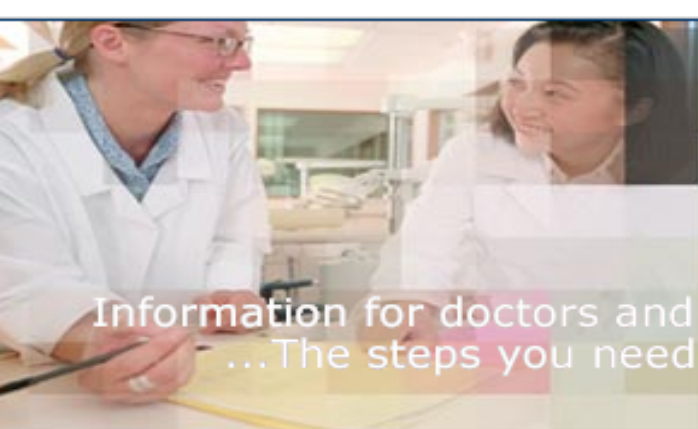


Linking Patients to Protocols: An Automated Registry Communication System

Rachel Richesson, PhD, MPH
University of South Florida College of
Medicine

*4th International Conference on
Rare Diseases and Orphan Drugs
Washington DC, May 20-22, 2008*



RARE DISEASES CLINICAL RESEARCH NETWORK

Information for doctors and patients...
...The steps you need to take action

Where do I need to go

Welcome! You have reached the home page for the Rare Diseases Clinical Research Network (RDCRN). Each Consortium within the network provides detailed information on several rare diseases.

What if I am unsure of which consortium to visit?

Scan the list to the right for a disease name. Once you have located it, click on the link for a brief description which will lead you to the correct consortium.

How will this consortium be useful to me?

You can take action! Once you have reached the correct consortium, you will be able to **join the contact registry** for clinical research trials. You will also find several helpful resources that include participating clinical center information, support and advocacy group information and other useful links.



Clinical Studies Open!



RDCRN Consortium Studies are opening!

[Learn More >>](#)

Last Updated: 11 May 2008

Look here for information on open studies and future studies

Clinical Research Consortia :

[Urea Cycle Disorders Consortium \[Study Information\]](#)

- N-Acetylglutamate Synthase (NAGS) Deficiency
- Carbamyl Phosphate Synthetase (CPS) Deficiency
- Ornithine Transcarbamylase (OTC) Deficiency
- Argininosuccinate Synthetase Deficiency (Citrullinemia I)
- Citrin Deficiency (Citrullinemia II)
- Argininosuccinate Lyase Deficiency (Argininosuccinic Aciduria)
- Arginase Deficiency (Hyperargininemia)
- Ornithine Translocase Deficiency (HHH) Syndrome

[Angelman, Rett, and Prader-Willi Syndromes Consortium \[Study Information\]](#)

- Angelman Syndrome
- Rett Syndrome
- Prader-Willi Syndrome

[CINCH - Consortium for Clinical Investigation of Neurological Channelopathies \[Study Information\]](#)

[Vasculitis Clinical Research Consortium \[Study Information\]](#)

- Wegener's Granulomatosis (WG)
- Microscopic Polyangiitis (MPA)
- Churg-Strauss Syndrome (CSS)
- Polyarteritis Nodosa (PAN)
- Takayasu's Arteritis (TAK)
- Giant Cell (Temporal) Arteritis (GCA)

[Rare Genetic Steroid Disorders Consortium \[Study Information\]](#)

- Congenital Adrenal Hyperplasia
- Androgen Receptor Defects
- Apparent Mineralocorticoid Excess (Low Renin Hypertension)

[Rare Thrombotic Diseases Consortium \[Study Information\]](#)

- Antiphospholipid Antibody Syndromes (APS)
- Heparin-induced Thrombocytopenia (HIT)

Consortium Website

- The consortium-specific public website provides the public with detailed information about the consortium and how to join the contact registry.

VASCULITIS CLINICAL RESEARCH CONSORTIUM

Welcome! The Vasculitis Clinical Research Consortium (VCRC) is an integrated group of academic medical centers, patient support organizations, and clinical research resources dedicated to conducting clinical research in different forms of vasculitis. It is our goal to improve the care of patients with Wegener's granulomatosis, microscopic polyangiitis, Churg-Strauss syndrome, polyarteritis nodosa, Takayasu's arteritis, and giant cell (temporal) arteritis.

We Can Help You:

- Become aware of clinical research and clinical trial opportunities
- Connect with expert doctors
- Connect with patient support groups
- Get help in managing your disease

What Is The VCRC?

Information for Patients:

- [Learn More](#)
- [Take Action](#)

Information For Physicians

Information For Investigators

News And Publications

Participating Clinical Centers

Contact Information

INFORMATION FOR PATIENTS

LEARN MORE

Unsured of a condition or looking to learn more? Look below to find definitions and more helpful information.

- + Wegener's Granulomatosis (WG)
- + Microscopic Polyangiitis (MPA)
- + Churg-Strauss Syndrome (CSS)
- + Polyarteritis Nodosa (PAN)
- + Takayasu's Arteritis (TAK)
- + Giant Cell (Temporal) Arteritis (GCA)

USEFUL LINKS

- [Useful Links](#)
- [Glossary of Terms](#)
- [Frequently Asked Questions](#)

TAKE ACTION

How Can I Help? - Why your Participation Matters...

Join the VCRC Contact Registry

Learn more about joining the VCRC Contact Registry

Updated! Find Information About Current Research

- [What is a Clinical Trial?](#)
- [Find Patient Support or Advocacy Groups](#)

INFORMATION FOR PHYSICIANS

Diseases defined...

Refer a Patient

Links and Resources

See also: Information for Investigators

New! Download the VCRC Contact Registry Paper Form

VCRC News and Publications

Vasculitis Foundation announces 2008 Vasculitis Symposium [Learn More >>>](#)

New VCRC Sites open in Toronto! [View open studies >>>](#)

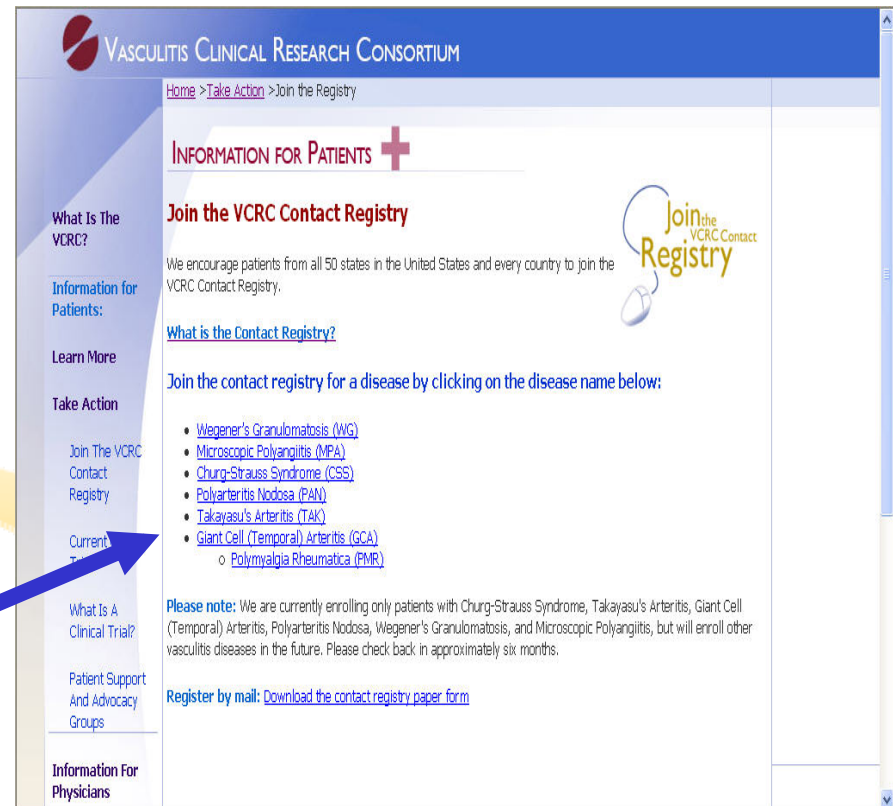
[VCRC Longitudinal Studies Flyers - Available for Download](#)

RDCRN Makes Contact Registry Available for Download to Facilitate Those Without Internet Access!

Glossary | Frequently Asked Questions | Contact Web Master | Accessibility | Disclaimer | Site Map
Return to RDCRN Main Page

Consortium Registry Links

- The public consortium website contains a “join the registry” page that provides links to the registry for each disorder.



VASCULITIS CLINICAL RESEARCH CONSORTIUM

Home > [Take Action](#) > Join the Registry

INFORMATION FOR PATIENTS

Join the VCRC Contact Registry

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

[What is the Contact Registry?](#)

Join the contact registry for a disease by clicking on the disease name below:

- [Wegener's Granulomatosis \(WG\)](#)
- [Microscopic Polyangiitis \(MPA\)](#)
- [Churg-Strauss Syndrome \(CSS\)](#)
- [Polyarteritis Nodosa \(PAN\)](#)
- [Takayasu's Arteritis \(TAK\)](#)
- [Giant Cell \(Temporal\) Arteritis \(GCA\)](#)
 - [Polymyalgia Rheumatica \(PMR\)](#)

Please note: We are currently enrolling only patients with Churg-Strauss Syndrome, Takayasu's Arteritis, Giant Cell (Temporal) Arteritis, Polyarteritis Nodosa, Wegener's Granulomatosis, and Microscopic Polyangiitis, but will enroll other vasculitis diseases in the future. Please check back in approximately six months.

Register by mail: [Download the contact registry paper form](#)

Information For Physicians

Join the VCRC Contact Registry

What Is The VCRC?

Information for Patients:

Learn More

Take Action

[Join The VCRC Contact Registry](#)

[Current Trials](#)

[What Is A Clinical Trial?](#)

[Patient Support And Advocacy Groups](#)

Registry Description

Description and Purpose of the Rare Diseases Clinical Research Network (RDCRN) Contact Registry

Thank you for your interest in this contact registry. The purpose of this contact registry is to provide an opportunity for individuals with a specific rare disease or disorder to register themselves to receive information about studies conducted by the Rare Diseases Clinical Research Network. You may also learn about progress being made towards treatment advances by researchers who specialize in your disease or disorder.

By joining the Contact Registry, you will be asked to provide information about you (or your child) and how you can be contacted. The registry will use that information to contact individuals who might qualify for participation in a research study. We may also use your contact information in order to communicate treatment information and sources.

Because of their rarity, researchers often have difficulty finding enough patients to study these diseases in order to understand and cure them.

To learn more about the Contact Registry and how it functions, click "Learn More".

[Learn More](#)

To join the contact registry, click "Join Contact Registry" and give authorization and complete the contact registry form.

[Join Contact Registry](#)

If you are currently a member of the Contact Registry and would like to discontinue enrollment or update your contact information, click "Update Info".

[Update Info](#)[Close Window](#)

Learn More

- A “learn more” page has in depth material pertaining to the contact registry.

The screenshot displays the website for the Vasculitis Clinical Research Consortium. The main navigation bar includes 'Home' and 'Take Action'. The page is titled 'INFORMATION FOR PATIENTS' with a red cross icon. A prominent section is 'Why is your participation important?' which includes a 'TAKE ACTION' graphic. Below this, there are sections for 'What is the Contact Registry?' and 'Who Can Join the Contact Registry?'. The left sidebar contains a menu with items like 'What Is The VCRC?', 'Information for Patients', 'Learn More', 'Take Action', 'Join The VCRC Contact Registry', 'Current Clinical Trials', 'What Is A Clinical Trial?', 'Patient Support And Advocacy Groups', 'Information For Physicians', 'Information For Investigators', 'News And Publications', 'Participating Clinical Centers', 'Contact Information', 'RDCRN Member Site Login', and 'Rare Diseases Medic Center'. The footer contains logos for RDCRN, NCRR, and NIAMS.

VASCULITIS CLINICAL RESEARCH CONSORTIUM

Home > Take Action

INFORMATION FOR PATIENTS +

Why is your participation important?

There are several ways that you can take action with the VCRC. You may [join our contact registry](#), participate in clinical trials, or participate with associated patient advocacy groups. More information about each is featured in this section.

TAKE ACTION

What is the Contact Registry?

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

You (or your child) are invited to participate in a research project that will develop a nation-wide registry for patients. This project is part of the Rare Disease Clinical Research Center Network, a network of clinical centers, each involved in research of specific rare disorders. This network is funded by the National Institutes of Health.

The reason we would like to create the contact registry is to inform patients and/or parents of patients in the contact registry of clinical research studies performed in our new multi-center Vasculitis Clinical Research Consortium. The Vasculitis Clinical Research Consortium has been established to collect information and perform research on vasculitis disorders including Takayasu's Arteritis, Giant Cell Arteritis, Polyarteritis Nodosa, Wegener's Granulomatosis, Microscopic Polyangiitis, and the Churg Strauss Syndrome. [Joining the contact registry](#) will help researchers identify and recruit patients who are eligible for participation in future research studies.

Information contained within this registry will be used for recruitment to research studies directed at improving our knowledge and treatment of these rare diseases. The continued efforts of researchers seek to improve the quality of life for all who are suffering from these rare diseases. The work of the researchers cannot occur without the 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 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 VCRC Contact Registry. Any patient with a confirmed or suspected diagnosis of a vasculitis disorder (such as Giant Cell Arteritis, Takayasu's Arteritis, Wegener's Granulomatosis, Microscopic Polyangiitis, Churg Strauss Syndrome, or Polyarteritis Nodosa) can register.

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.

Once you have entered and submitted this information online, the data will be stored in a secure, computerized database. No personal identifying information (such as your name, address, telephone number) will be given to anyone without your expressed approval.

[Click here to join the Contact Registry!](#)

Home | Glossary | Frequently Asked Questions | Contact Web Master | Accessibility | Disclaimer | Site Map
Return to RDCRN Main Page

RDCRN Member Site Login

Rare Diseases Medic Center

NCRR NIAMS RDCRN



RARE DISEASES

Authorization Agreement

- Registrants must agree to the HIPAA compliant authorization in order to register with the contact registry.

Authorization Agreement

RDCRN Contact Registry

Please read the following carefully. The submission of information in the registry will be considered your consent to the following statements.

Authorization Statement for Use and Disclosure of Protected Health Information

The University of South Florida and the Rare Diseases Clinical Research Network Data and Technology Coordinating Center understand that information about you/(your minor child) and your/(your minor child's) health is personal, and we are committed to protecting the privacy of that information. You are granting your authorization before we use your/(your minor child's) protected health information (PHI) for the purpose of providing you notification of the availability of clinical studies or trials and updates on the results of clinical studies and trials performed within the Rare Diseases Clinical Research Network. This form memorializes your authorization for us to use your PHI for this purpose and helps us make sure that you are properly informed of how this information will be used and/or disclosed.

By agreeing to this document you are permitting the Data and Technology Coordinating Center (DTCC) to use PHI collected about you/(your minor child) so that they may contact you with information about availability of clinical studies or trials and provide updates on the results of clinical studies and trials performed by the Rare Diseases Clinical

I HEREBY GIVE permission to the Rare Diseases Clinical Research Network to use the information I provide to the online patient registry. I understand that if I enter my or my child's contact information, I agree to be contacted about future research studies. I understand that if I do provide my or my child's name or other contact information, neither will be identified by name or any traceable identification in any report published or distributed without my permission.

By clicking the "I Agree" button you are agreeing to the terms and conditions of the statements above.

If you consent to the statements above please click "I Agree".

Registry Form

- The registration form contains information such as disorder, date of diagnosis, etc.
- The registrant enters their information into the web based form and registers with the Contact Registry.

Contact Registry Form * Field required to Register

Patient Information (Person with disorder)

Disorder: *

Date of Diagnosis (if you don't know the entire date, please enter as much as possible)
 05 JAN 2008
 Day (DD) Month (MM) Year (YYYY)

Date of Birth (if you don't know the entire date, please enter as much as possible)
 04 JUL 1972
 Day (DD) Month (MM) Year (YYYY)

Place of birth:
 Country:
 State/Province:
 Country:

Gender: *
 Male Female

Ethnicity:
 Hispanic or Latino Not Hispanic or Latino

Race (check all that apply):
 American Indian/Alaska Native
 Asian
 Black or African American
 Native Hawaiian/Pacific Islander
 White
 Unknown

Contact Information (Person to be contacted)

First name: Last name:

Mailing Address:

City: State/Province:

Country: Zip/Postal Code:

Primary Phone: Secondary Phone:
 (e.g., 888-888-1232) (e.g., 888-888-1232)

Email address: Fax:
 (e.g., 888-888-1232)

I am a: *
 Patient Parent/Guardian

How do you prefer us to contact you?
 Email Phone Mail Fax Withdraw

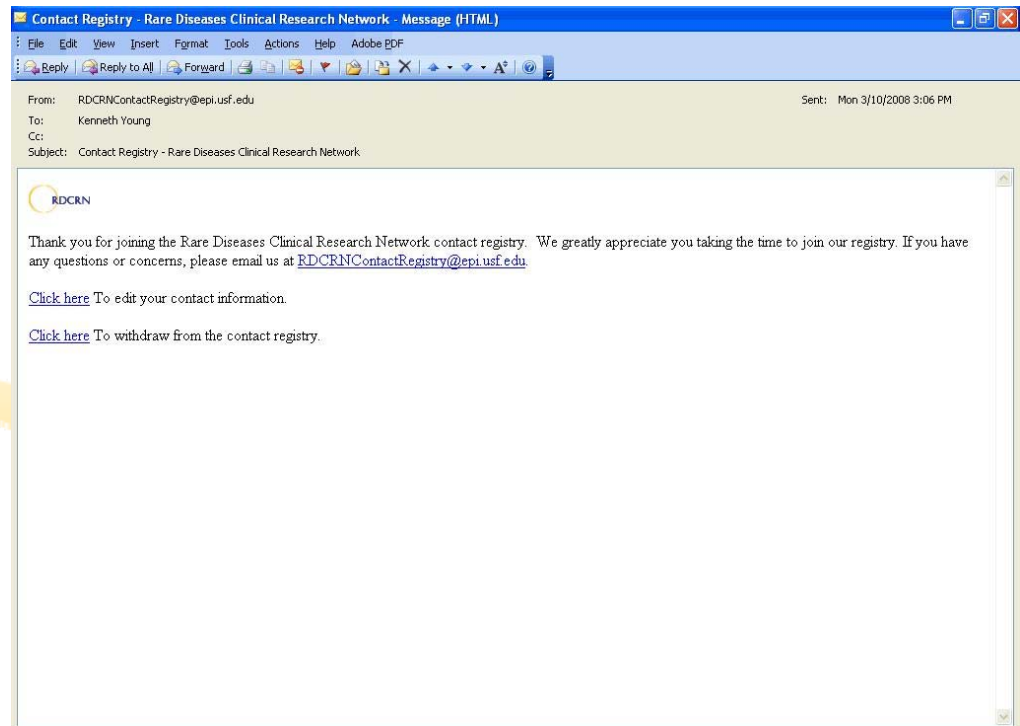
What is the best time to contact you?
 Morning Afternoon Evening Any time of day Never

How did you find out about us?
 Support group / Foundation
 Internet
 Word of mouth
 Publication
 Medical Professional
 Media
 Other

Register Print Cancel

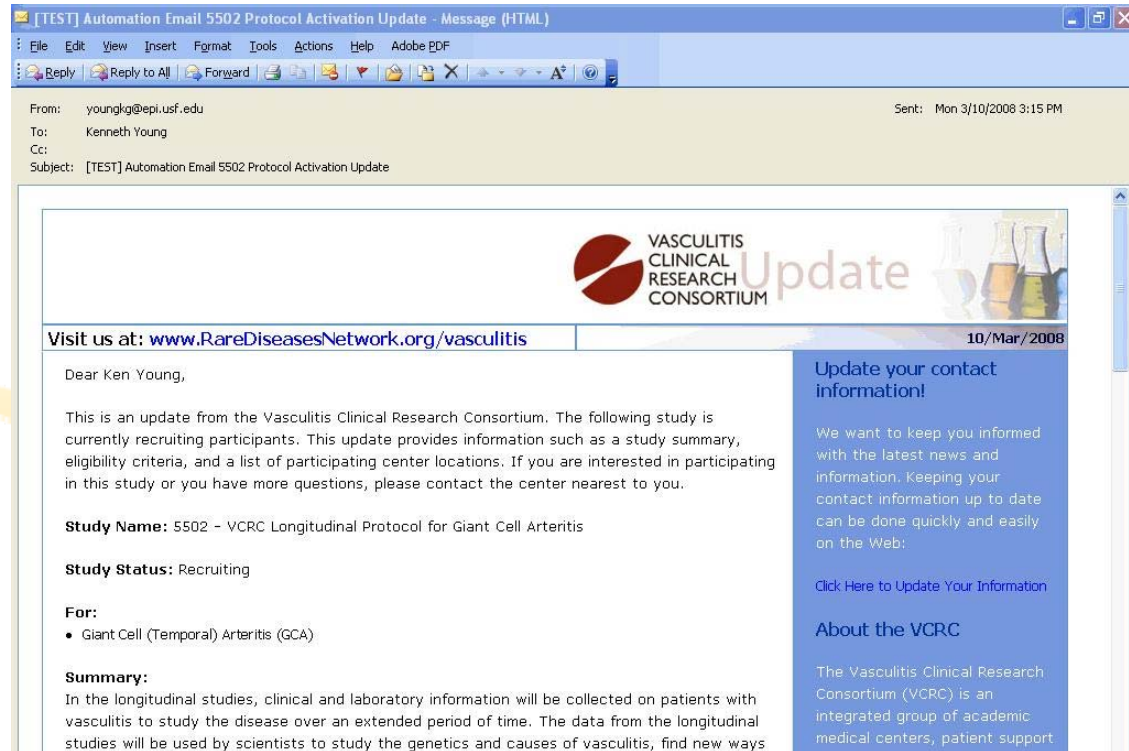
Registry Acknowledgement Email

- An acknowledge Email is sent to the registrant after they register or if they update their information.
- The registrant is provided with links in the Email to update their information.



Sample Study Email

- Emails can be sent to registrants by automations, schedules, or manually.
- The Emails can be customized to include content from each Consortium.
- A template is created to improve Email efficiency and quality.



Sample Study Email


Update


Visit us at: www.RareDiseasesNetwork.org/vasculitis
10/Mar/2009

Dear Ken Young,

This is an update from the Vasculitis Clinical Research Consortium. The following study is currently recruiting participants. This update provides information such as a study summary, eligibility criteria, and a list of participating center locations. If you are interested in participating in this study or you have more questions, please contact the center nearest to you.

Study Name: S502 - VCRC Longitudinal Protocol for Giant Cell Arteritis

Study Status: Recruiting

For:

- Giant Cell (Temporal) Arteritis (GCA)

Summary:

In the longitudinal studies, clinical and laboratory information will be collected on patients with vasculitis to study the disease over an extended period of time. The data from the longitudinal studies will be used by scientists to study the genetics and causes of vasculitis, find new ways to track disease and predict responses, to understand how to treat patients, and much more.

How to Participate:

In order to participate in a study, you must personally contact the study coordinator of any of the participating institutions by phone or by e-mail. Please use the information below to inquire about participation.

- Boston University School of Medicine**
Boston, Massachusetts
Principal Investigator: Peter Merkel, MD MPH
Contact Person: Ashley Leavitt
Office: 617-624-2520
Email: leavitt@bu.edu
- Cleveland Clinic Foundation (VCRC)**
Cleveland, Ohio
Principal Investigator: Carol Langford, MD, PhD
Contact Person: Katherine Tuttle
Office: 216-444-9626
Email: TUTTLEK@ccf.org
- Johns Hopkins University**
Baltimore, Maryland
Principal Investigator: Philip Sles, MD, PhD
Contact Person: Corinna Bellina
Office: 410-500-4390
Email: cbellin4@jhmi.edu
- Mayo Clinic (VCRC)**
Rochester, Minnesota
Principal Investigator: Deean Ytterberg, MD
Contact Person: Jane Jaufft
Office: 507-255-4502
Email: jaufft.jane@mayo.edu
- Mount Sinai Hospital, Toronto**
Toronto, Ontario Canada
Principal Investigator: Simon Caville, MD
Contact Person: Sara Sutherland, RN, BScN
Office: 416-586-6616
Email: SSutherland@mountsinai.ca
- St. Joseph's Hospital, Toronto**
Hamilton, Ontario Canada
Principal Investigator: Isador Khalil, MD
Contact Person: Sandra Messier, RCT
Office: 905-531-5961
Email: smessier@sjps.ca

Participation in research studies is voluntary. Deciding not to participate in a research study does not affect your ability to receive care at any of our Clinical Centers or from other physicians.

Update your contact information!

We want to keep you informed with the latest news and information. Keeping your contact information up to date can be done quickly and easily on the web.

[Click here to Update Your Information](#)

About the VCRC

The Vasculitis Clinical Research Consortium (VCRC) is an integrated group of academic medical centers, patient support organizations, and local research resources dedicated to conducting clinical research in different forms of vasculitis and improving the lives of patients with vasculitis.

The Vasculitis Clinical Research Consortium is part of the National Institutes of Health's Rare Diseases Clinical Research Network. The VCRC continues to grow and is working on several new research projects concerning vasculitis. Check back with the VCRC website regularly for updates.

www.RareDiseasesNetwork.org/vasculitis

This e-mail has been sent to Ken Young (youngk@bepi.usf.edu) from the Rare Diseases Clinical Research Network (RDCRN).

About the RDCRN

www.RareDiseasesNetwork.org

The Rare Diseases Clinical Research Network (RDCRN) was established by the National Institutes of Health (NIH) to develop research studies for rare diseases, and to encourage cooperative partnerships among researchers at the networks' 10 clinical centers around the world. This increased cooperation may lead to discoveries that will help treat and perhaps prevent these rare diseases, as well as produce medical advances that will benefit the population in general.

The Rare Diseases Clinical Research Network is comprised of a Data and Technology Coordinating Center and 10 consortia (groups) studying nearly 50 rare diseases.

Automated Communications

- Typical automations:
 - Welcome
 - New Study
 - New Clinical Site
 - Periodic (every 6 months)
- Automations can be customized by study or consortium

Administrator Interface: Campaign Manager

Contact Registry Campaign Manager

File View

RDCRN
Contact Registry Campaign Manager

Campaign List

- Campaigns
 - VCRC Initial
 - UCDC Initial
 - BMF Initial
 - VCRC Pittsburg Seminar
 - UCDC January 2007
 - GDMCC January 2007
 - Automation ARPWS
 - Automation BMF
 - Documents
 - Consortia
 - Search Criteria
 - Automations
 - Automation CLIC
 - Automation GDMCC
 - Automation GSDC
 - Automation CINCH
 - Automation RLDC
 - Automation RTDCRC
 - Automation UCDC
 - Documents
 - Consortia
 - Search Criteria
 - Automations
 - Scheduled Email Update UCDC [ACTIVE]
 - Automation VCRC
 - Documents
 - Consortia
 - Search Criteria
 - Automations
 - 5502 Protocol Activation Update [ACTIVE]
 - 5503 Protocol Activation Update [ACTIVE]
 - 5504 Protocol Activation Update [ACTIVE]
 - 5505 Protocol Activation Update [ACTIVE]
 - 5506 Protocol Activation Update [ACTIVE]
 - Scheduled Email Update VCRC

Campaigns Registrants

New

	Campaign	Description	Type	Status	Date	Consortia	Documents	Contact History
▶	VCRC Initial	VCRC Initial ...	Newsletter	Active	14/Jul/2006	Consortia	Documents	Contact Hist...
	UCDC Initial	UCDC Initial ...	Newsletter	Active	02/Aug/2006	Consortia	Documents	Contact Hist...
	BMF Initial	BMF Initial C...	Newsletter	Active	24/Aug/2006	Consortia	Documents	Contact Hist...
	VCRC Pitts...	Seminar in Pi...	Newsletter	Active	06/Oct/2006	Consortia	Documents	Contact Hist...
	UCDC Janu...	UCDC Janu...	Newsletter	Active	10/Jan/2007	Consortia	Documents	Contact Hist...
	GDMCC Ja...	GDMCC Jan...	Newsletter	Active	22/Jan/2007	Consortia	Documents	Contact Hist...
	Automation ...	Angelman, R...	Newsletter	Active	12/Mar/2007	Consortia	Documents	Contact Hist...
	Automation ...	BMF Consort...	Newsletter	Active	12/Mar/2007	Consortia	Documents	Contact Hist...
	Automation ...	Cholestatic L...	Newsletter	Active	12/Mar/2007	Consortia	Documents	Contact Hist...
	Automation ...	GDMCC Aut...	Newsletter	Active	12/Mar/2007	Consortia	Documents	Contact Hist...
	Automation ...	Automation ...	Newsletter	Active	12/Mar/2007	Consortia	Documents	Contact Hist...
	Automation ...	Automation ...	Newsletter	Active	12/Mar/2007	Consortia	Documents	Contact Hist...
	Automation ...	Automation ...	Newsletter	Active	12/Mar/2007	Consortia	Documents	Contact Hist...
	Automation ...	Automation ...	Newsletter	Active	12/Mar/2007	Consortia	Documents	Contact Hist...

Logged On User: Kenny Young

Administrator Interface: Campaign Configuration

Campaign Automation

Campaign: Automation BMF

Campaign: Automation BMF

Consortium: Bone Marrow Failure Disease Consortium

Protocol:

Document: Merged Study Update - BMF (Email)

Teleform Document:

Automation Description: Scheduled Email Upate BMF

Action: Scheduled Email

Active:

Campaign Search Criteria: BMF All

Execution Date: 12/Mar/2007

Use Execution Date:

Recurrence:

Recurrence Pattern

Recur every 6 month(s)

Recurrence Range

Start: 30/Apr/2007

No end date

End by: 01/Aug/2007

Save

RA

Administrator Interface: Registrant Information and Updates

File View

RDCRN Contact Registry Campaign Manager

Campaign List

- ⊕ BMF Initial
- ⊕ VCRC Pittsburg Seminar
- ⊕ UCDC January 2007
- ⊕ GDMCC January 2007
- ⊕ Automation ARPWS
- ⊕ Automation BMF
 - ⊕ Documents
 - BMF Blank Template
 - Merged Study Update - BMF (Email)
 - Protocol Activation Document
 - ⊕ Consortia
 - ⊕ Search Criteria
 - ⊕ Automations
 - 5401 Protocol Update
 - 5403 Protocol Update
 - 5405 Protocol Update
 - 5406 Protocol Update [ACTIVE]
 - Scheduled Email Update BMF [ACTIVE]
- ⊕ Automation CLIC
- ⊕ Automation GDMCC
- ⊕ Automation GSDC
- ⊕ Automation CINCH
- ⊕ Automation RLDC
- ⊕ Automation RTDCRC
- ⊕ Automation UCDC
 - ⊕ Documents
 - Merged Study Update - VCRC (Email)
 - VCRC Blank Template
 - VCRC Protocol Update Email
 - ⊕ Consortia
 - Vasculitis Clinical Research Consortium
 - ⊕ Search Criteria
 - ⊕ Automations
 - 5502 Protocol Activation Update [ACTIVE]
 - 5503 Protocol Activation Update [ACTIVE]
 - 5504 Protocol Activation Update [ACTIVE]

Campaigns | **Registrants**

Consortium:

Disease:

Contact Name:

Contact Email Address: Missing Email Address

Contact Method:

Contact State: Miles: From ZipCode:

User Id:

Failed to Contact:

Campaign (Contact History): Not Contacted

Date From (Contact History):

Date To (Contact History):

Display Withdrawn:

Select	Contact Name	Disease	Consortium	Contact Method	Address	Email	Phone	UserId/Key
[Empty Table]								

Select All

Logged On User: Kenny Young

Enrollment

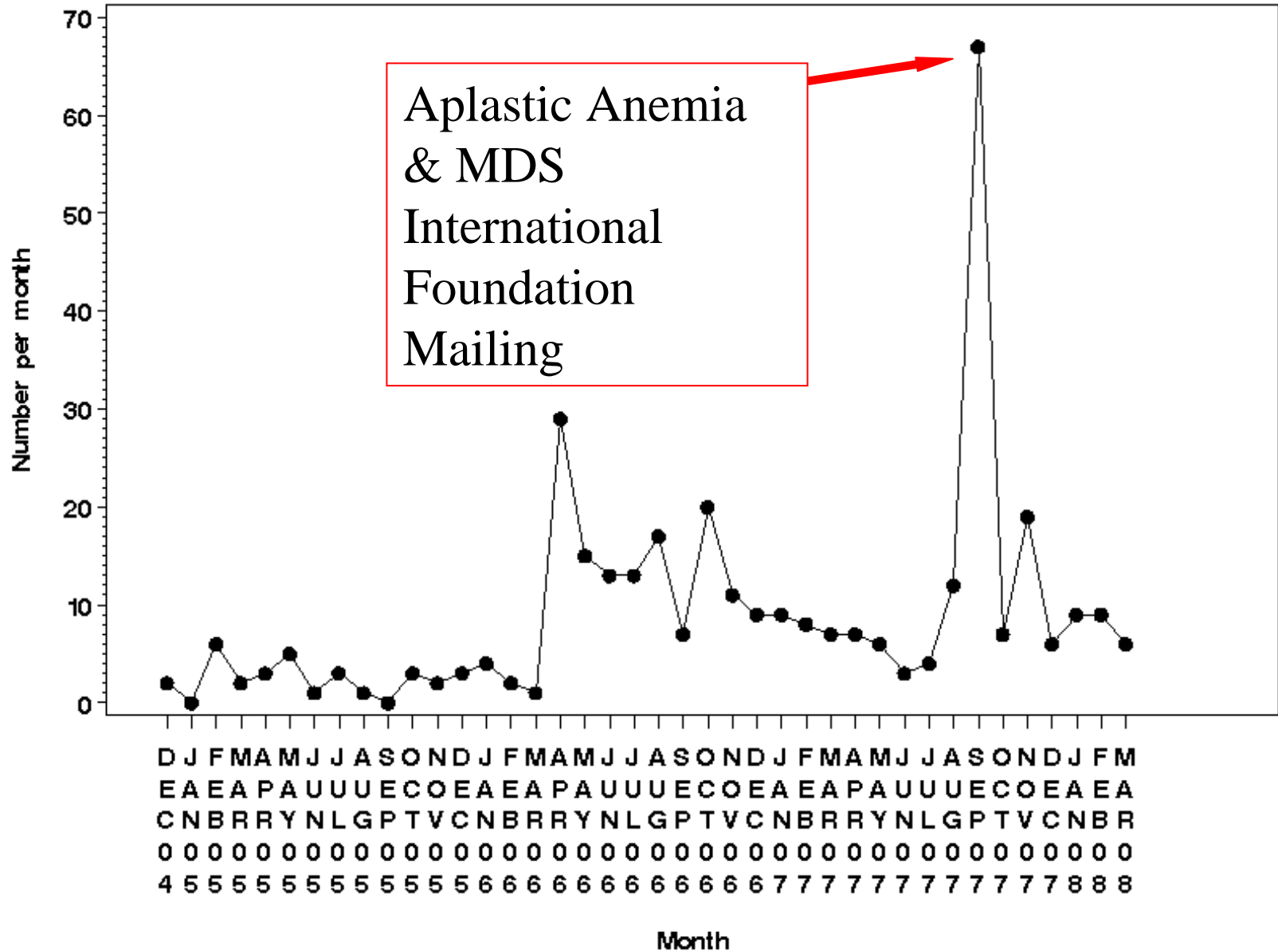
Consortia	N
Angelman, Rett, & Prader-Willi Syndromes	715
Bone Marrow Failure Disease	356
Cholestatic Liver Disease	263
Neurologic Channelopathies	134
Genetic Diseases of Mucociliary Clearance	251
Genetic Steroid Disorders	46
Rare Lung Disease	247
Rare Thrombotic Disease	384
Urea Cycle Disorders	254
Vasculitis	1710
<i>Total</i>	4360

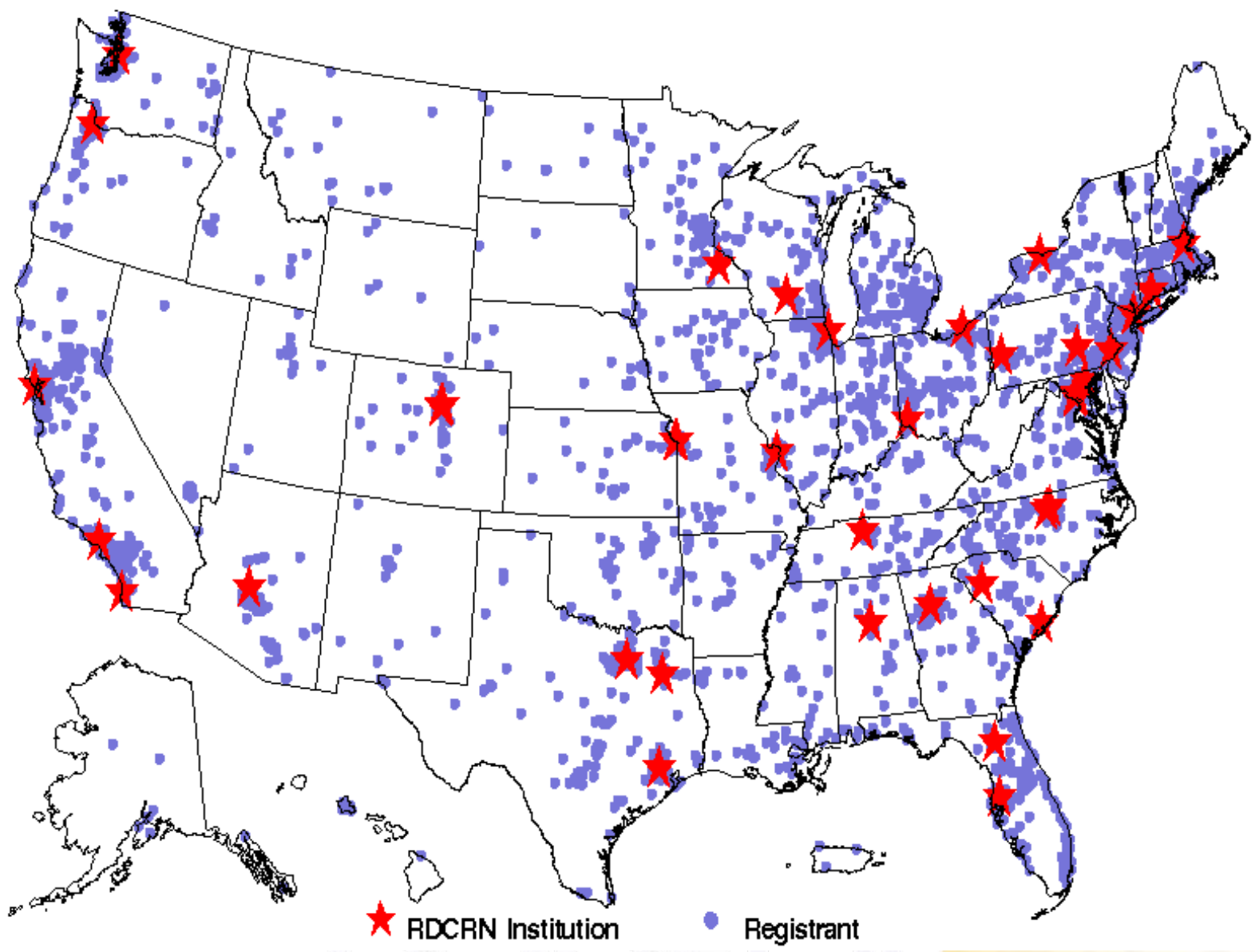
Preferred Contact Method

Contact Method	N	Percent
Email	3106	71%
Fax	10	0%
Mail	558	13%
Missing	41	1%
Phone	645	15%
	<i>4360</i>	<i>100%</i>

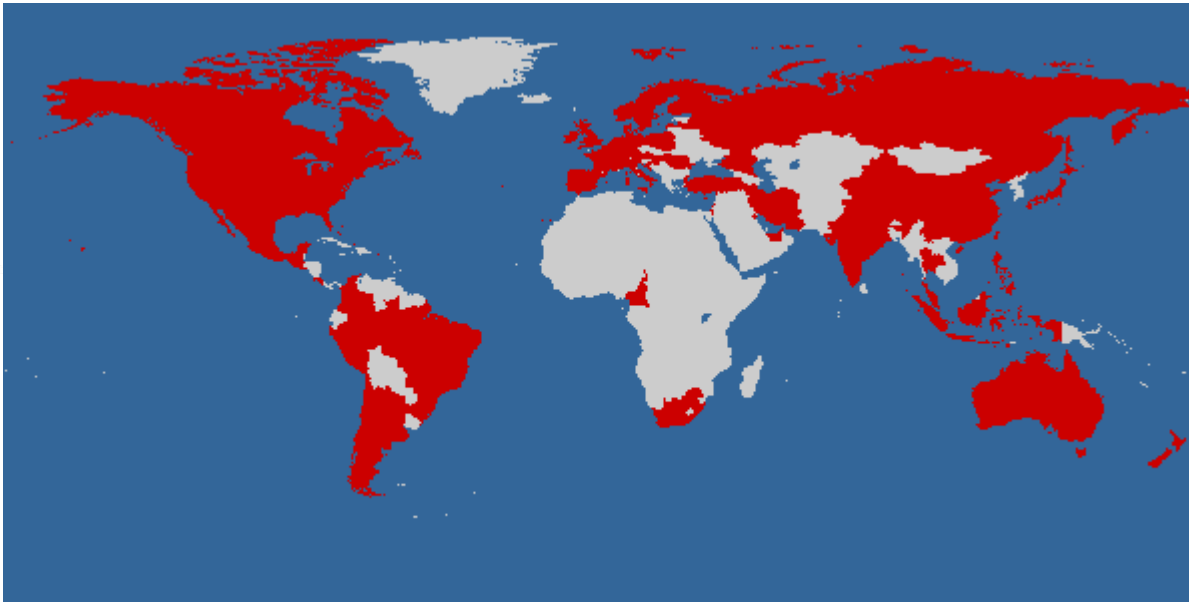
Reported Referral Method

How did you find out about us?	N	Percent
Internet	1896	43%
Media	6	0%
Medical Professional	365	8%
Missing	24	1%
Other	99	2%
Publication	141	3%
Support Group or Foundation	1742	40%
Word of mouth	87	2%
	4360	100%





Contact Registry's Global Reach



- 10-15% of the Contact Registry have non-US, non-Canada Addresses
- Over 60 countries represented

Enrollment on Clinical Studies

Clinical Research Consortium	Total # of Contact Registrants Eligible for Studies (% enrolled in selected studies)	Within 200 miles of a clinical site	Within 100 miles of a clinical site
		Total # of Contact Registrants Eligible for Studies (% enrolled in selected studies)	Total # of Contact Registrants Eligible for Studies (% enrolled in selected studies)
Angelman, Rett, & Prader-Willi	648 (15%)	213 (20%)	98 (29%)
Bone Marrow Failures	282 (7%)	96 (13%)	46 (17%)
Genetic Diseases of Mucociliary Clearance	315 (27%)	52 (42%)	32 (28%)
Urea Cycle Disorders	207 (27%)	97 (37%)	68 (43%)
Vasculitis	1325 (6%)	482 (8%)	229 (12%)
All sampled studies (12, 2/23/2006)	2777 (12%)	940 (16%)	473 (21%)

Summary

- Data-driven and automated system
- Fast
- Customizable
- Flexible
- Scalable
- Effective

Future Directions

- Additional diseases
- Link to Clinical Trial Registries to expand the database of available studies
- Ability to download information sheets to discuss with own physician

Acknowledgements

- NIH Office of Rare Diseases (ORD)
- NIH National Center for Research Resources (NCRR)
- RDCRN Coalition of Patient Advocacy Groups (CPAG)

- Ken Young
- Jennifer Lloyd

Questions

Jeffrey Krischer, PhD

Jeffrey.Krischer@epi.usf.edu

Rachel Richesson, PhD, MPH

Rachel.Richesson@epi.usf.edu