

Linking Patients to Protocols: An Automated Registry Communication System

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RARE DISEASES



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

RARE DISEASES
CLINICAL RESEARCH
NETWORK

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 \[Study Information\]](#)

Autism Spectrum Disorders (ASDs) (Future Studies)

[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)
Disseminated Intravascular Coagulation (DIC)

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

[RDCRN Member Site Login](#)

[Rare Diseases Media Center](#)

INFORMATION FOR PATIENTS

LEARN MORE

Unsure 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](#)

[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](#)

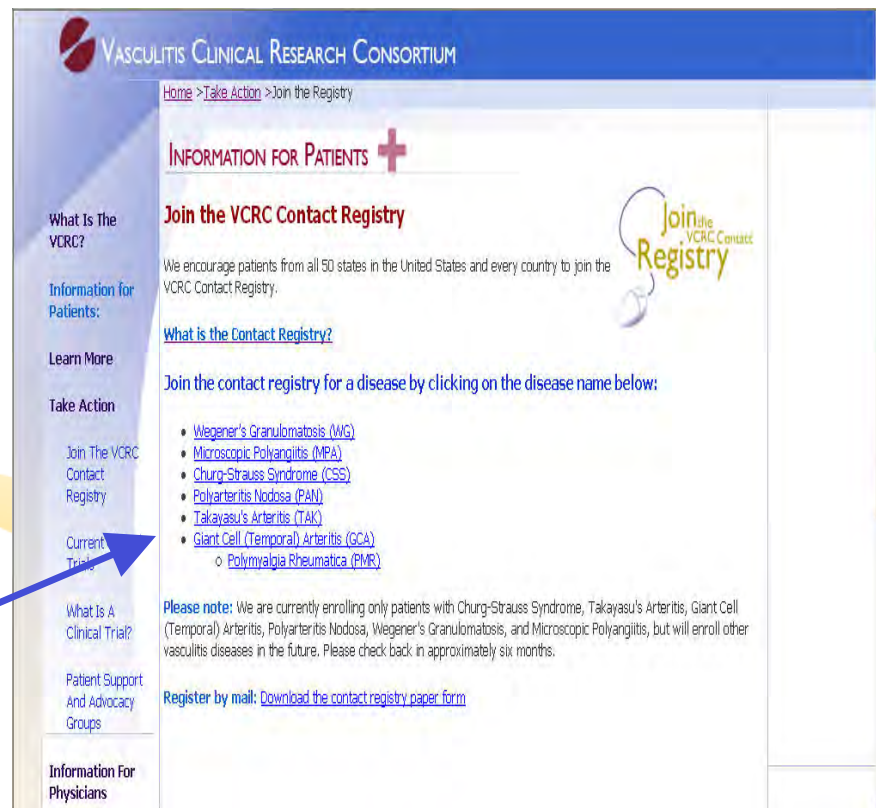
RDCRN Makes Contact Registry Available for Download to Facilitate Those Without Internet Access!

[Glossary](#) | [Frequently Asked Questions](#) | [Contact Web Master](#) | [Accessibility](#) | [Disclaimer](#) | [Site Map](#)
Return to RDCRN Main Page

[RDCRN](#) [NCRR](#) [NIAMS](#)

Consortium Registry Links

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



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.



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 for Register

Patient Information (Person with disorder)

Disorder:

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

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

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., 800-555-1212) (e.g., 800-555-1212)

Email address: Fax:
 (e.g., 800-555-1212)

I am a: *
☒ Patient ☐ Parent/Guardian

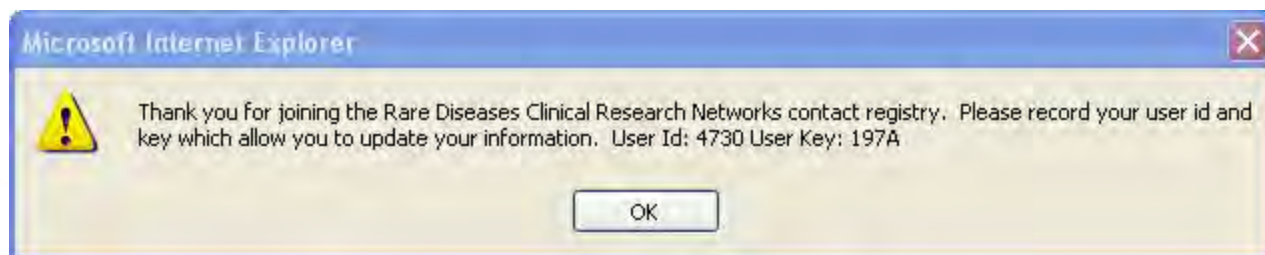
How do you prefer us to contact you?
☒ Email ☐ Phone ☐ Mail ☐ Fax ☐ Withdraw

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

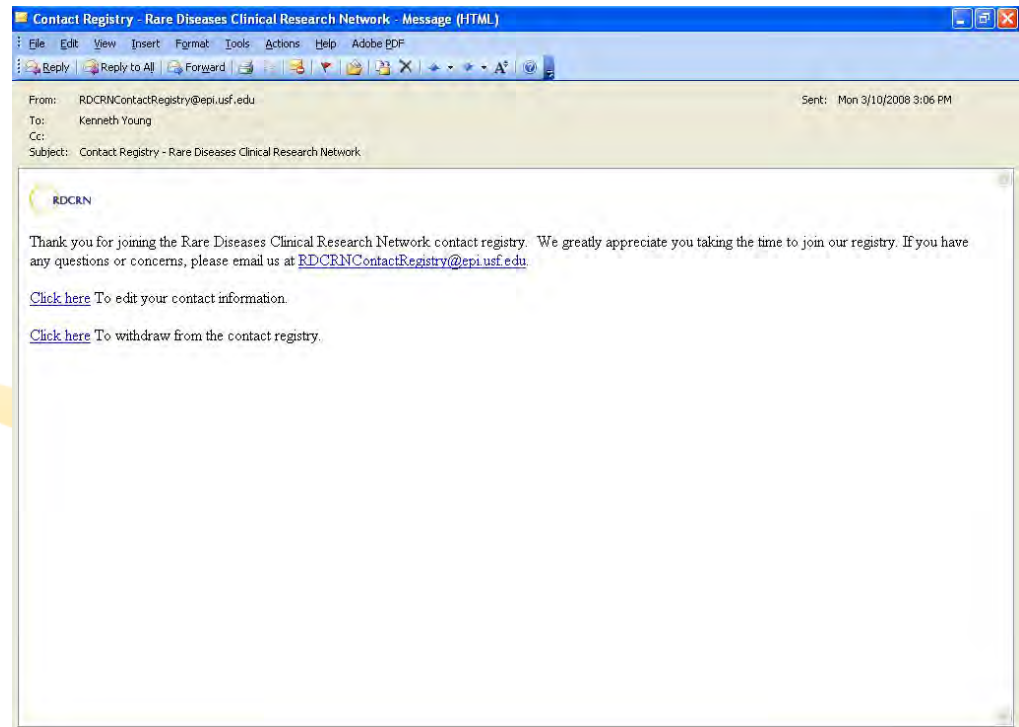
Register Print Cancel

Registry Acknowledgement Box



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.

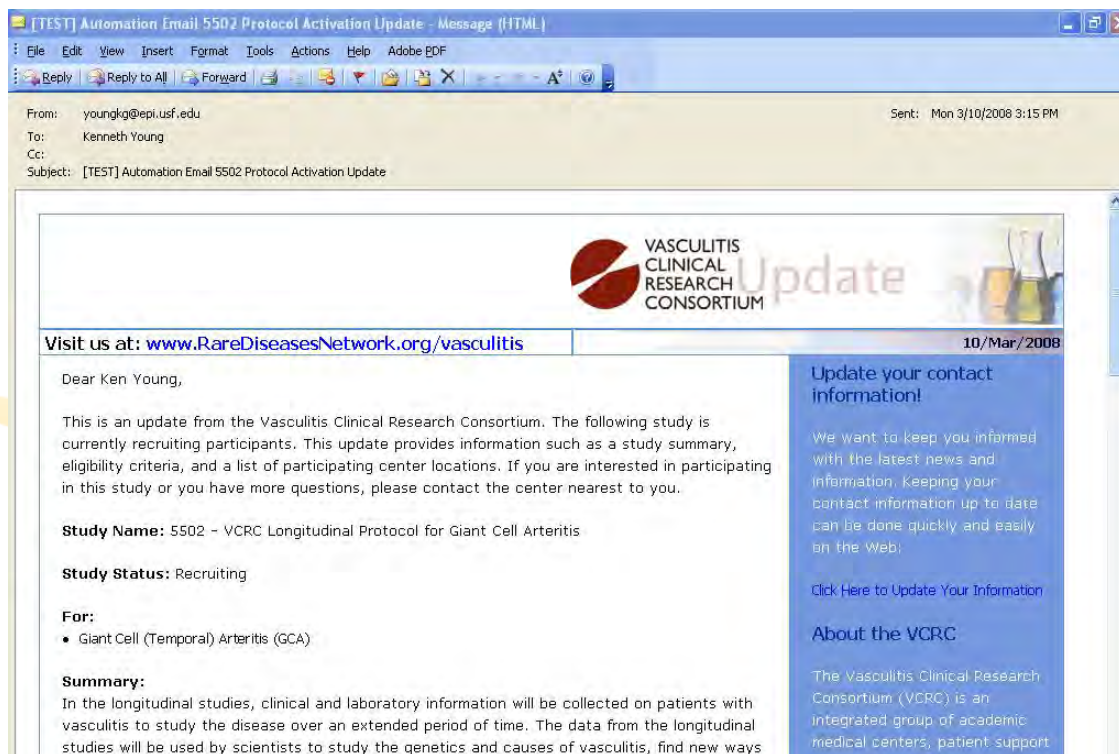


Sample Study Email

- 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

10/16/2010

Dear Kim 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 email. Please use the information below to inquire about participation.

- Boston University School of Medicine**
 Boston, Massachusetts
 Principal Investigator: Peter Merkel, MD MHS
 Contact Person: Ashley Leavitt
 Office: 617-441-2509
 Email: leavitt@bu.edu
- Cleveland Clinic Foundation (VCRC)**
 Cleveland, Ohio
 Principal Investigator: Carol Langford, MD, PhD
 Contact Person: Katherine Tuhli
 Office: 216-444-9606
 Email: TUHKL@ccf.org
- Johns Hopkins University**
 Baltimore, Maryland
 Principal Investigator: Philip Shen, MD, PhD
 Contact Person: Cynthia Bellini
 Office: 410-505-4390
 Email: cbellin@jhmi.edu
- Mayo Clinic (VCRC)**
 Rochester, Minnesota
 Principal Investigator: Steven Ytterberg, MD
 Contact Person: Jane Squith
 Office: 507-255-4522
 Email: squith.jane@mayo.edu
- Mount Sinai Hospital, Toronto**
 Toronto, Ontario Canada
 Principal Investigator: Simon Sutherland, MD
 Contact Person: Sara Sutherland, RN, BSc
 Office: 416-596-6616
 Email: S.Sutherland@utoronto.ca
- St. Joseph's Hospital, Toronto**
 Hamilton, Ontario Canada
 Principal Investigator: Isador Shalit, MD
 Contact Person: Sandra Messier, RCT
 Office: 905-533-5981
 Email: smessier@sjhs.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 make sure we have your contact information up to date. Please let us know if you have any changes to your contact information. We will keep your information confidential.

Click here to update your information

About the VCRC

The Vasculitis Clinical Research Consortium (VCRC) is an international group of academic medical centers, academic health systems, and clinical research centers that are working together to advance the understanding of vasculitis and improve the lives of patients with vasculitis.

The Vasculitis Clinical Research Consortium is part of the Rare Diseases Clinical Research Network, the first national network of research centers for rare diseases in the United States. The network is a public-private partnership between the National Institutes of Health (NIH) and the private sector.

www.RareDiseasesNetwork.org/vasc

This e-mail has been sent to Kim Young (youngg@bu.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, provide ongoing support and guidance to researchers at the laboratory, clinical centers, and in the world. This network (consortium) has been established to help these and others prevent these rare diseases as well as provide medical advances that will benefit the population in general.

The Rare Diseases Clinical Research Network is composed of a Data and Technology Coordinating Center and 21 Consortium (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 P...	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...
	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

Administrator Interface: Registrant Information and Updates

Contact Registry Campaign Manager

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
 - Urea Cycle Disorders Consortium
 - Search Criteria
 - UCDC All
 - Automations
 - Scheduled Email Update UCDC [ACTIVE]
- Automation VCRC
 - 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: -Select-

Disease:

Contact Name:

Contact Email Address: ☐ Missing Email Address

Contact Method: ☐ Email

Contact State: ☐ Alabama Miles: From ZipCode:

User Id:

Failed to Contact: ☐

Campaign (Contact History): ☐ Not Contacted

Date From (Contact History):

Date To (Contact History):

Display Withdrawn: ☐

Search Save Search Load Saved Search Clear Search

Select	Contact Name	Disease	Consortium	Contact Method	Address	Email	Phone	UserId/Key
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☐ Select All

Contact Selected Registrants

Logged On User: Kenny Young

Enrollment

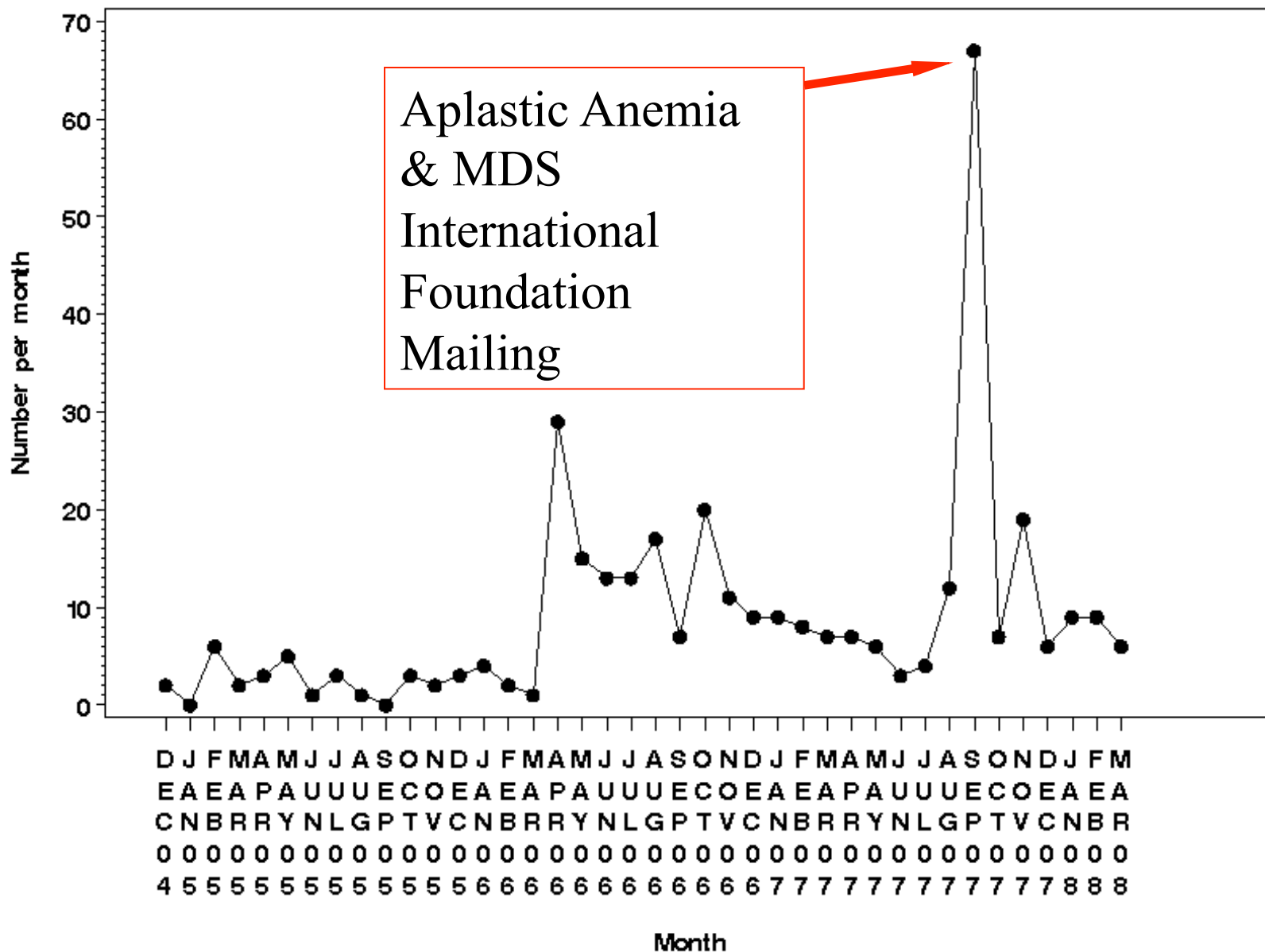
Consortia	N
Angelman, Rett, & Prader-Willi Syndromes	791
Bone Marrow Failure Disease	387
Cholestatic Liver Disease	290
Neurologic Channelopathies	178
Genetic Diseases of Mucociliary Clearance	276
Genetic Steroid Disorders	60
Rare Lung Disease	262
Rare Thrombotic Disease	463
Urea Cycle Disorders	281
Vasculitis	1899
Total	4887

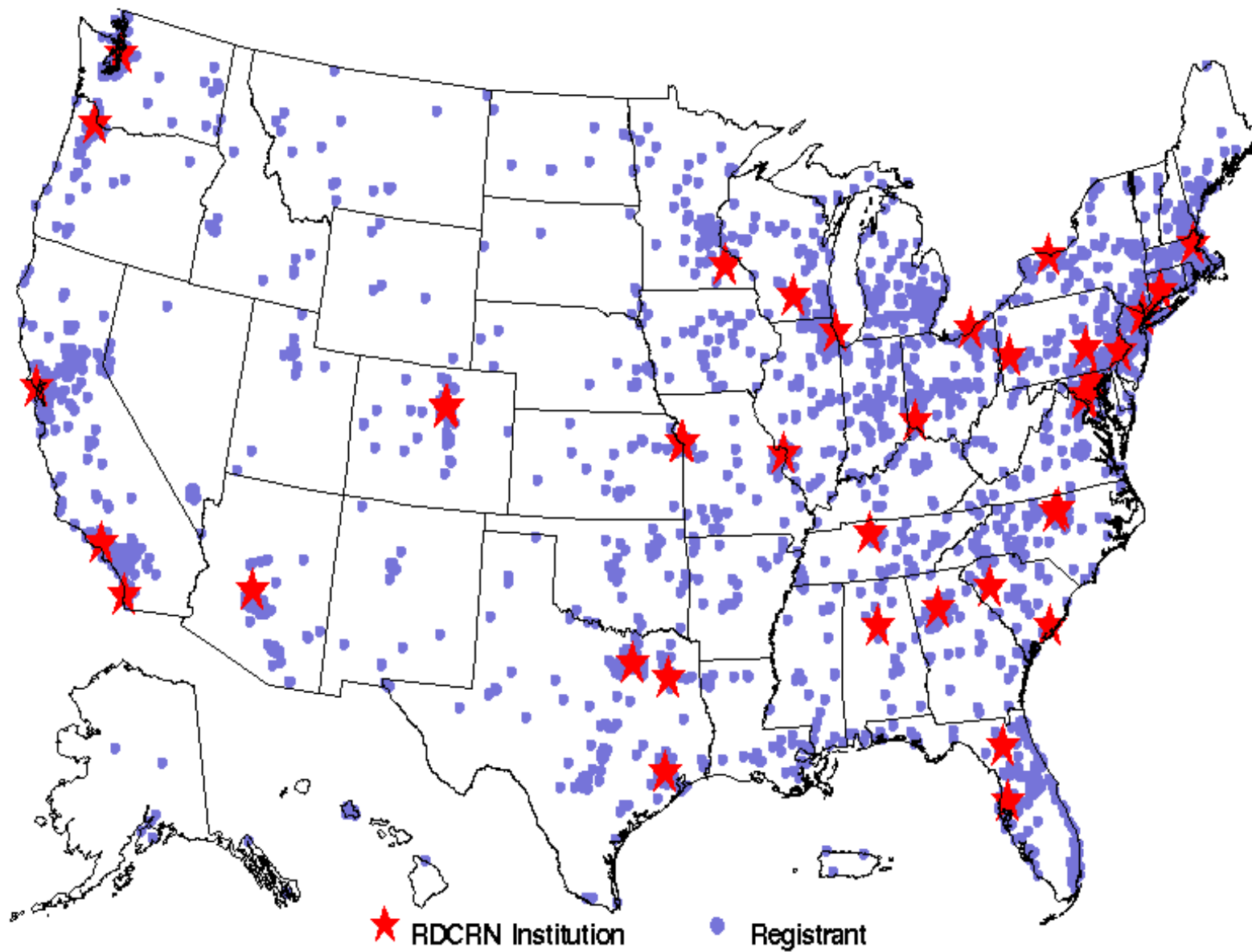
Preferred Contact Method

Contact Method	N	Percent
Email	3500	72%
Phone	715	15%
Mail	607	12%
Fax	12	0%
Missing	53	1%
	4887	100%

Reported Referral Method

How did you find out about us?	N	Percent
Internet	2119	45%
Media	7	0%
Medical Professional	410	8%
Missing	29	1%
Other	112	2%
Publication	146	3%
Support Group or Foundation	1867	38%
Word of mouth	97	2%
	4887	100%





Contact Registry's Global Reach



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

Country	N	%
Missing	22	0.52
United States	3593	85.45
American Samoa	1	0.02
Argentina	9	0.21
Australia	70	1.66
Austria	2	0.05
Bahamas	1	0.02
Belgium	2	0.05
Bolivia	2	0.05
Brazil	11	0.26
Bulgaria	1	0.02
Cameroon	1	0.02
Canada	177	4.21
Chile	3	0.07
China	2	0.05
Colombia	2	0.05
Costa Rica	1	0.02
Croatia	3	0.07
Cuba	1	0.02
Cyprus	1	0.02
Denmark	2	0.05
Egypt	2	0.05
El Salvador	3	0.07
Estonia	1	0.02
Finland	3	0.07

Country	N	%
France	3	0.07
Germany	12	0.29
Greece	1	0.02
Guatemala	1	0.02
Hong Kong	1	0.02
Hungary	1	0.02
Iceland	1	0.02
India	22	0.52
Indonesia	1	0.02
Iran	1	0.02
Ireland	11	0.26
Israel	5	0.12
Italy	7	0.17
Japan	4	0.10
Kenya	1	0.02
Kuwait	1	0.02
Luxembourg	1	0.02
Malaysia	2	0.05
Malta	1	0.02
Mexico	7	0.17
Nepal	1	0.02
Netherlands	10	0.24
New Zealand	12	0.29
Norway	1	0.02
Peru	1	0.02

Country	N	%
Philippines	2	0.05
Poland	4	0.10
Portugal	4	0.10
Puerto Rico	2	0.05
Romania	2	0.05
Russia	1	0.02
Singapore	4	0.10
South Africa	13	0.31
Spain	8	0.19
Sweden	5	0.12
Switzerland	3	0.07
Taiwan	2	0.05
Thailand	5	0.12
Trinidad And Tobago	1	0.02
Turkey	3	0.07
Ukraine	1	0.02
United Arab Emirates	1	0.02
United Kingdom	119	2.83
	4205	100.00

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

- Effective
- Patient-driven
- Automated
- Scalable

RARE DISEASES

Future Directions

- Expand types of data collected
 - Define registry vs. (research) study?
- Additional diseases
- Additional sources for research studies
- Support community-based research

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

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Questions

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RARE DISEASES