Disease Advocacy Organizations

What can Reg4All do for you? And is it the best option for your organization?
Reg4ALL Extends DAO Reach

- Some DAOs have beat the bushes and can’t find any more ‘members’
- Some DAOs are so new that they don’t have robust membership yet
- Some DAOs are expanding their work to related syndromes
- Some DAOs need less expensive recruitment methods
The Changing Landscape

• Individuals and families do not join just one organization to meet their needs anymore
• Affected individuals surf the internet, catching waves here and there, but never JOIN anything
• Individuals need multiple ways of interacting to stay engaged
• People expect gamification and feedback, instant gratification, reward for participation
• Participants want to see how compare with one another—desire to be like others AND see how they are extraordinary
The Changing Landscape, Cont’d

• People expect systems to be personal and responsive to who they are
• Affected individuals are not affected by one condition, or state of health
• The ‘consumer movement’ is penetrating health, and people expect to control their information
• Every article, new announcement on sharing information calls for granular privacy preferences
What We DAO Fear

- That cross-disease platform registries will decrease our donor base
- That if we don’t control all of the data on our disease, we won’t be able to call the shots
- That others won’t do it right
- That common platform registries won’t meet our very special needs
- That it will be too expensive
- That we don’t have adequate time, staff, resources, expertise
- That it is too confusing
What the World Demands if We are to Make a Difference Sooner than Later

• Risking as much as our ‘member’ families do
• Collaboration/cooperation/networks (incl. cross disease research)
• Connectivity
• Pathways/systems/phenotype approaches
• Fast tracking all of the aspects of the solution at the same time
• Teams of teams
• Not constraining innovation by the industries of old (Larry Lessig: The Future of Ideas)
• Getting people to stick to our DAO (stickiness)
• Be what we are asking others to be
Let’s View Reg4ALL from the Individual’s Perspective
Empowering Affected Individuals to Join Us in Building Registries

- Disease Specific Data Elements
- Common Data Elements
- Gamified Survey

Reg4ALL.org
Introducing Disease InfoSearch

Are you looking for disease information or support? You’ve come to the right place! Simply type in the name of a condition above and Disease InfoSearch will locate quality information from a database of more than 13,000 conditions and thousands of support groups and foundations.

Are you looking for even more detailed information? Are you a healthcare provider or researcher? Select from a wide variety of fields in the Advanced Search to help you find listings of services and research interests that match your needs.

BIG NEWS
National Innovation Challenge Winner!

Reg4ALL was selected as the winner of the Collaborate/Activate Innovation Sanofi Challenge. Reg4ALL is an initiative to create a comprehensive, crowdsourced, cross-disease registry to help accelerate translational research for 1,000+ diseases.

Genetic Alliance and their team of partner organizations will receive $200,000 to bring their vision to life.

In order to learn more about how Reg4ALL can benefit you and persons you care about, click here.

Sign up for Reg4ALL

Answer questions about your health. Let resources you select come to you. ... all while protecting your privacy.

Use privacy tools from Private Access to share key pieces of health information with medical researchers, disease advocacy groups, and others ONLY YOU select.

Contribute to Disease InfoSearch

To list your organization or add information about a disease, please access your account.
Or, Enter Via DAO Website

BECOME A MEMBER

Please select all answers that apply to you

- Person diagnosed with a rare neuroimmunological condition
- Relative of a person diagnosed with a rare neuroimmunological condition
- Caregiver
- Medical Professional
- Researcher
- Other

Done
Prader-Willi syndrome is a complex genetic condition that affects many parts of the body. At birth, babies with PWS have poor muscle tone and a weak cry. Initially, they are slow feeders and appear undernourished. The feeding problems improve after infancy and often between 2 to 4 years of age, children with PWS become very focused on food and have difficulty controlling their appetite. The overeating often results in rapid weight gain and obesity. Individuals with PWS also often have developmental delays and less-than-average adult height. PWS is caused by missing or non-working genes on chromosome 15. Most cases are not inherited, but occur randomly.

Source: Genetic and Rare Diseases Information Center (GARD), supported by ORR-NCATS and NHGRI.
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Source: Genetic and Rare Diseases Information Center, NHGRI.
Reg4ALL

Or Your Brand

Disease Specific Data Elements
Common Data Elements
Gamified Survey

Trust
Education
Engagement

Privacy Assured with PrivateAccess

Reg4ALL.org
Video of YOU

Donna’s Recommendations

These suggestions give you more comfort and control relative to your confidential medical information. For a particular trial, give advance permission for researcher contact. For other studies, set your contact preferences to give you notice of researcher interest before you consent to contact.

- Lower privacy concerns
- Moderate privacy concerns
- Greater privacy concerns

Advocacy & Support Groups

- DIS-listed organizations serving your condition: Allow
- Non-profit organizations serving your condition: Allow

Discover My Data: what’s this?

Contact Me: what’s this?

Use My Data: what’s this?

Go Back  Customize  Next
### Privacy Settings

#### Advocacy & Support Groups
- DIS-listed organizations serving your condition: Allow
- Non-profit organizations serving your condition: Allow

#### Medical Researchers
- Researchers recommended by a DIS-listed organization serving your condition: Allow
- IRB-approved research addressing your condition: Allow
- All researchers: Allow

#### Data Analysis
- "Compare with others" feature: N/A
- "Show related content" feature: N/A
- Genetic Alliance Translational Research Network: Allow
- Oracle Health Sciences Network: Allow
- Newly-Released Data Analysis Platforms: Ask Me

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**Your Organization**

**Your Partner Researchers**
Reg4ALL

Or Your Brand

Disease Specific Data Elements
Common Data Elements
Gamified Survey

Trust
Education
Engagement

Disease InfoSearch
Powered by Genetic Alliance

Reg4ALL.org
The interactive survey

Reg4All has simple and engaging surveys that ask general questions about your health and medical conditions.

Have fun finding out how you compare with others!

What’s next?
Demo of Reg4ALL

demo.reg4all.org
Let’s View Reg4ALL from the Organization’s Perspective
Join Reg4All

13,000 disease pages
Hundreds of thousands of visitors
High SEO

Pharma and Biotech analyzing data to choose diseases

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About Disease InfoSearch
About Genetic Alliance
Partners
Terms and Conditions
Privacy Policy
DIS Dashboard

Mission Statement
PXE International initiates, conducts and funds research on pseudoxanthoma elasticum (PXE), educates clinicians and supports affected individuals.

Conditions Served: pseudoxanthoma elasticum

Organization Name: PXE International, Inc.
Acronym: PXE
Status of Org: Incorporated Nonprofit
Type of Org: Condition specific, International
Have 501(c)3 Status: Yes
Year Established: 1995

Annual Budget: $275,000

Accelerate the drug development process

GaugeRx is an online tool that assists users in deciding how to most effectively leverage their existing resources to advance the research and development portfolio for their disease of interest...
Creating Questions in Reg4All

app.traitwise.com
Where Does the Data Go?

• Two databases –
  – Secure Private Access account (Privacy Bureau like PayPal is for our credit and bank info)
  – HIPAA compliant database in the cloud (vendor to Genetic Alliance)

• Individuals determine:
  – Who can ‘discover it’ – de-identified index
  – Who can contact them (they can ‘join’ your DAO)
  – Who can ‘use’ their data – download it and do a study (requires IRB approval, Genetic Alliance has an IRB available for approvals)
• View and download data and reports through RecruitSource app
  – Access to de-identified data
  – Access to contact information
  – Full data download
  – ALL of the above are dependent on the privacy settings of each individual.
Registry Pro

• Genetic Alliance Registry and BioBank
  – A la carte registry option
  – Based on RedCap
    • 647 Institutions
    • 87,000 researchers
    • Fully customizable
    • Fields are standards-based and can be automatically coded
    • Data dictionary
    • Capable of longitudinal data entry forms
    • Report-building
Integrated Vision
Funding Dependent

Privacy Layer
Privacy Preferences powered by Private Access

Survey Gamification
Powered by Traitwise

Standards and coding
Powered by RedCAP

Teaser Questions

Common Data Elements

Disease Specific Questionnaire

EMR, Images, Lab Reports, etc.
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<td>Collect longitudinal data</td>
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Vote by going to:
http://www.changemakers.com/healthbiz