

RESEARCHING LIFE to CHANGE LIVES

Volunteer Orientation to the PFOND Project

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Celebrating CMMT 15

science

growth

people

global reach

innovation

Goals for the Session

- Describe the project and status (Wyeth)
- Review issues of copyright and participation agreement (Wyeth)
- Introduce the software system (Puya)
- Describe the content sections (Cynthia)

What is the PFOND Project

- A collaborative project driven by volunteers to create and maintain online information for underserved communities of people struggling with rare disorders

Why Rare Disorders?

- If a disorder is well-served by existing internet resources, we will NOT seek to divide a community with a competing service
- Volunteers have limited time to track information and can therefore provide better coverage
- These families are most under-served by existing resources

Is there a need for PFOND?

- Communities are often served transiently by a site (e.g. Facebook page), but such resources are almost always transiently maintained
- The types of information sought suggest a common structure for presenting information
- Ultimately the need will become clear through the level of participation with the service.

What does the name “PFOND” mean?

- Original project focus was restricted to neuro-developmental disorders
- Name stood for “Portal for Families Overcoming Neuro-developmental Disorders”
- It sounds better than PFORD? (Rare Disorders)

What information will PFOND provide?

- Overview of the disorder
- Links to relevant news and research publications
- A public discussion board
- An opportunity for members of a community to interact

Potential Disorders (paper counts)

- Leigh syndrome (238)
- Hartnup Disorder (108)
- Rothmund-thomson syndrome (164)
- Adrenoleukodystrophy (1811)
- Aarskog–Scott syndrome (faciogenital dysplasia) (28)
- Hardikar syndrome (5)
- Mesomelia-synostoses syndrome (3)
- Haim-Munk Syndrome (8)
- *Pelizaeus-Merzbacher Disease (261)*
- *Cornelia de Lange Syndrome (300)*
- *Prader-Willi syndrome (2517)*
- *Rett Syndrome (2118)*
- *Angelman Syndrome (1180)*
- *Williams-Beuren Syndrome (227)*
- *Aicardi-Goutieres Syndrome (123)*
- *Aicardi Syndrome (??)*
- *Kabuki Syndrome (186)*
- *Adams-Oliver Syndrome (100)*
- *Floating-Harbor Syndrome (42)*
- *Joubert Syndrome (417)*

Providing Feedback

- This is the beta-testing stage of PFOND. We expect for you to reveal problems or limitations with the system. Please be vocal in expressing your frustrations and ideas for improvements.

Email Deluge

- For now we will be sending communications by email. If the amount of email becomes annoying, let us know and we will shift to a different mechanism.

Recognition and Rewards?

- The ultimate reward is satisfaction from the interaction with a community of users
- We can and will report on your volunteer work at your request. We will attempt to be quantitative in our reports to recognize the amount of volunteer effort (volunteers who show greater commitment should receive greater recognition)
- Volunteers who help shape the direction of the project may be recognized on future publications describing the project

Retirement from Volunteering

- You may withdraw from participation at any time.
- If you have not logged into the system in the past 45 days, we will contact you by email to see if you want to withdraw. No response within 10 days will be taken as withdrawal. You may return in the future at your request.

Copyright

- One of the greatest risks for PFOND is for participants to post content that belongs to someone else. Such postings are not approved, nor desired.
- All text and images are under copyright, and the restrictions on re-posting may not be apparent.
- Therefore **assume that you do NOT have permission to post the words, illustrations or images created by anyone but yourself.**

Initial PFOND Contributor Agreement

- We will continue to seek input from UBC as to the appropriate participant agreement for PFOND volunteers. Thus we may seek your agreement to a modified or different agreement in the future.
- For now, we want to protect the ability to keep the sites active beyond the period of time you are engaged as a volunteer. Therefore we are asking that you agree to work under an initial set of terms intended to promote broad access to your contributions

Initial PFOND Contributor Agreement

- You grant the PFOND project (and therefore UBC) permission to post your content on the website.
- Because multiple volunteers may interact in creating a site, you acknowledge that your words and illustrations may be modified by others for display on the PFOND system.
- As separating your work from the work of others may be extremely difficult or impossible, you agree that your permission will not be revoked lightly.
- If in the extreme case you wish to erase your contributions from the system, you recognize that such an action could have extreme negative consequences on a community of users and project participants, and would therefore allow a period of 90 days for the work to be removed in order to allow replacement of the material.
- You agree to the sharing of your content (and all PFOND content) under the terms of the Attribution-NonCommercial-ShareAlike 3.0 Unported (CC BY-NC-SA 3.0) license
 - <http://creativecommons.org/licenses/by-nc-sa/3.0/>
 - Purpose: no commercial use of work, but free use OK with credit to original source

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Tasks to complete

- Choose disorder
- Create account
- Confirm access works
- Post comment to discussion board
- Add hyperlink
- Add test content to overview page
- Set-up RSS feed for PubMed
- Set-up RSS feed for Google News
- Create overview summary and post
- Create image (or provide photo) for your page
- Add welcome message
- Set-up “text tooltips”
- Continuing tasks
 - Add more links
 - Refine overview
 - Highlight news articles
 - Participate in discussions

Milestones / Goals

(These are motivational dates – as volunteers we appreciate your efforts
and will not impose strict deadlines)

- Confirm access to system by 21 November
- Complete first 5 steps by 28 November
- Complete RSS feeds by 5 December
- Complete tasks up to posting an overview summary by 19 December
- We will convene for a mid-point celebration in late January 2012