Volunteer Orientation to the PFOND Project

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Celebrating CMMT 15

science   growth   people   global reach   innovation

Organization of Session

- **Overview – Wyeth**
- System Highlights- Puya
- Editor Experience – Tuhina
- Open discussions/interactions

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Goals for the Session

- Describe the project and status
- Review issues of copyright and participation agreement
- Introduce the software system
- Describe the content sections

What is the PFOND Project

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

Focus on Under-served Rare Disorders

- The families are most under-served by existing resources

- Volunteers can provide more comprehensive information within limited time

- If a disorder is well-served by existing internet resources, we will NOT seek to divide a community with a competing service

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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.

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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)

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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

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.

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Recognition and Reward

- 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

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Initial Paper

- Portal for Families Overcoming Neurodevelopmental Disorders (PFOND): implementation of a software framework for facilitated community website creation by non-technical volunteers

- Xin (Cynthia)Ye, Isaiah Ng, Puya Seid-Karbasi, Tuhina Imam, Wyeth W. Wasserman , PhD

- Preparing for submission to Journal of Medical Internet Research

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**.

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