

Real-time Family Support Through Social Media



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Family Support

- ▶ Genetic conditions are stressful
 - Financial concerns
 - Mental health
 - Divorce
 - Other children

- ▶ Rare conditions and rural areas

Inclusion Criteria

- ▶ Families of kids ages 0 –18 with:
 - Hearing Loss
 - Sickle Cell Disease
 - PKU
 - Cystic Fibrosis
 - Marfan syndrome
 - Ehlers Danlos Syndrome

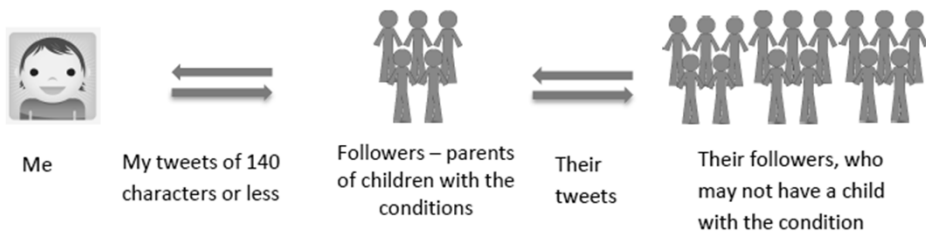


RTFSSM

Created Facebook group for each condition

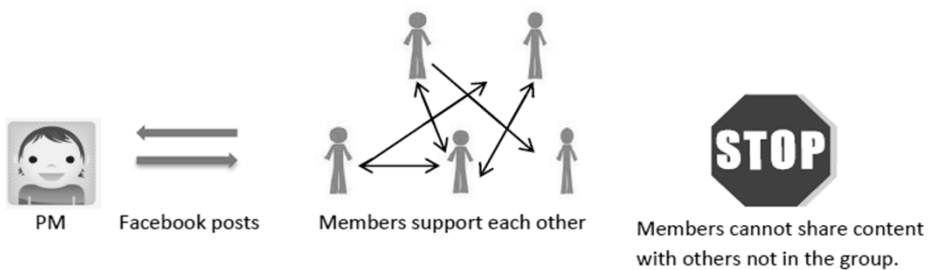
- ▶ Connected families
- ▶ Shared health information in *plain language*
- ▶ Provided advocacy alerts

Twitter



- IRB and Marketing department had concerns about privacy
- Useful for promoting Facebook groups

Facebook Groups vs. Pages

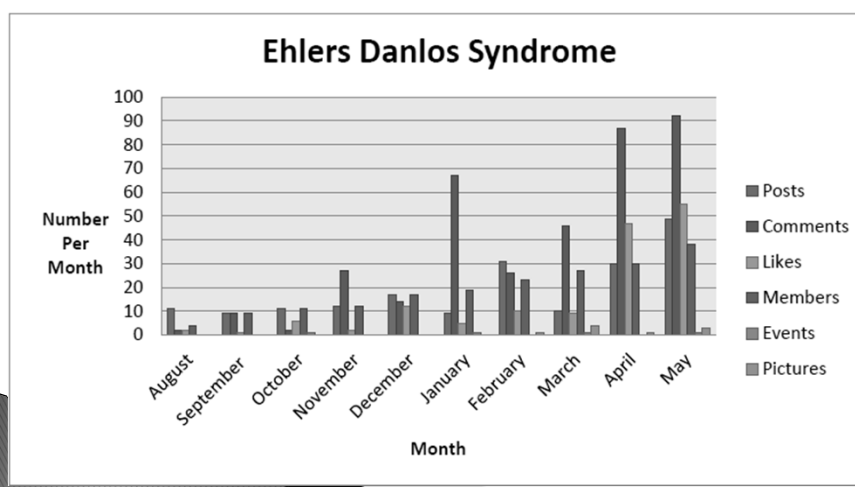


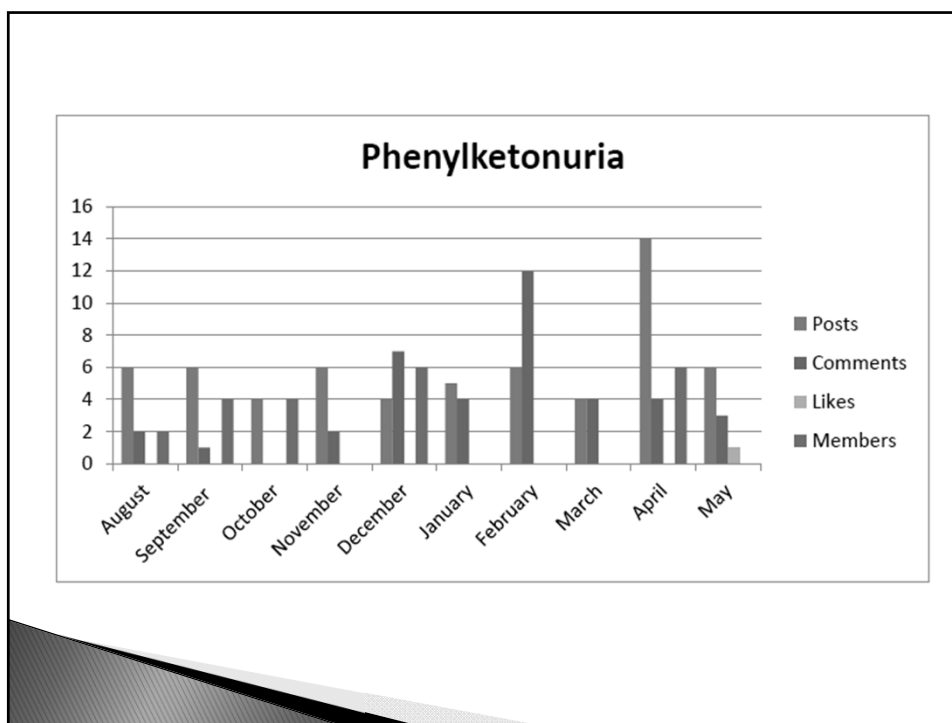
- More interaction; data collection more difficult
- Balance need for patient privacy with visibility
- Hard to determine the location of those asking to join

Results

- ▶ Some organizations have restrictive guidelines
- ▶ Gaining buy-in among health care providers critical, but difficult
- ▶ Fragmented care, but national organizations helped
- ▶ Parent initiated a Williams Syndrome group
- ▶ Need to expand telehealth
- ▶ Interest in raising awareness, but not sure how

- ▶ Activity level and type of activities varied by group
 - Time commitment from organization
 - Perceived unmet needs among families
 - Use of relationship building techniques





Results

- ▶ Participants were very appreciative – content included:
 - Emotional support
 - Policy discussions
 - “Has anyone had ____ symptom?”
 - Success stories: “My daughter advocated for herself in gym today; I’m so proud of her!”
- ▶ Youth skype, email each other
- ▶ Children with sickle cell disease need more intensive services
 - Lack internet access, food, transportation, access to care
 - Alternative marketing and partnerships

Family to Family Iowa

- ▶ Family Navigators (FNs) are employed parents of children with special health care needs
- ▶ Assisted several families
 - Coping with psychosocial aspects of condition
 - Developing self-advocacy skills
 - Working with schools to create IEP and 504 plans
 - Completing paperwork to obtain needed equipment
- ▶ Groups interested, but not able to meet requirements
 - Family Navigators
 - Organizational representation

Sustainability

- ▶ F2F IA was original plan – groups could not meet requirements
- ▶ Did not ask health care providers to monitor content
 - Potential HIPAA violations
 - Provider time and reimbursement
 - Did not want to encourage one institution over another
 - Some may take advantage of provider expertise
- ▶ Identified 2-3 members to serve as moderators
- ▶ Suggestions to keep content fresh and accurate
- ▶ Encouraged members to “Like” ASK Resource Center Facebook page to connect with F2F IA

Evaluation

- ▶ Events, chat features popular on Facebook
- ▶ Most access social media 1+ time per day
- ▶ Definition of a friend has changed
- ▶ Teens may not discuss the condition, but background of understanding is helpful
- ▶ Social media can eliminate communication and cultural barriers

Conclusion

- ▶ Opportunities for greater collaboration between Genetics Department, specialty areas, and statewide
- ▶ Participants appreciative of efforts and accepting of minor mistakes
- ▶ Major influence on future outreach and communication
- ▶ Must work within Facebook or Twitter systems
- ▶ Social media is always changing

Thank you!

Questions?