

# Real-time Family Support through Social Media

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## Family Support

- ▶ Genetic conditions are stressful<sup>1</sup>
  - Financial concerns
  - Mental health
  - Divorce
  - Guilt
  - Siblings
  
- ▶ Rare conditions and rural areas

## RTFSSM Goals

Enhance communication/education to families using social media

- ▶ Connect families to peer-to-peer support
- ▶ Link existing support groups to Family to Family Iowa
- ▶ Improve awareness of importance of family support

## RTFSSM

Connect Iowa families with six genetic conditions:

- Hearing Loss
- Sickle Cell Anemia
- PKU
- Cystic Fibrosis
- Marfan Syndrome
- Ehlers-Danlos Syndrome



## RTFSSM Content

Provide information on:

- health topics in *plain language*
- legislation and policy
- transitioning to adulthood
- communicating with medical providers

## Why Social Media?

- ▶ Need to get message 3-5 times before believing it<sup>2</sup>
- ▶ Need to get health messages from experts and peers<sup>2</sup>



## Facebook

- ▶ User creates a personal profile
- ▶ RTFSSM adds to correct group
- ▶ RTFSSM approves and monitor posts
- ▶ Post pictures, articles, & thoughts for comment
  
- ▶ 500 million+ active users
- ▶ 50% of users log in on any given day
- ▶ Average 130 friends

## Twitter

- ▶ Messages that are 140 characters or less (tweets)
- ▶ Interact with friends, celebrities, or organizations
  
- ▶ 1 billion tweets/week
- ▶ 460,000 new accounts per day
- ▶ 6,396 tweets/second on 1/1/2011 in Japan
- ▶ 8 employees in 2008; now 400

## Marketing

- ▶ Postcards
- ▶ Newsletters
- ▶ Collaborator's websites
- ▶ State and national support groups

## Ensuring Privacy and Quality

- ▶ Adherence to IRB protocols
- ▶ Assistance in learning to use social media
- ▶ Recent, non-biased info from reputable organizations

The screenshot shows the Twitter profile page for Iowa Hands & Voices (@IAHandV). The profile includes a logo of a hand with a spiral, the name "Iowa Hands & Voices", and the handle "@IAHandV Iowa". The bio states: "Providing unbiased support for families with hearing loss." and provides a website link: "http://www.handsandvoices.org/chapters/iowa.htm". The page shows 0 tweets, 4 following, 0 followers, and 0 listed. A "What's happening?" text box is visible, with the text "from Iowa City, IA" and a "Tweet" button. The right sidebar contains an "About you" section with statistics, a "You recently followed" list with profiles like "UnitedWayBlount" and "gnresoundus", and a "What's next?" section with the prompt "Write your first Tweet!".

The screenshot shows a YouTube video player for a video titled "UI Children's Hospital - Celiac Disease". The video is uploaded by "UIChildrens" and has 37 videos in the channel. The video content shows a male doctor in a white lab coat speaking in front of a bookshelf and a banner for the University of Iowa Children's Hospital. The banner text includes "University of Iowa Children's Hospital", "University of Iowa Health Care", and "Changing Medicine. Kids Changing Lives.". Below the video player, there are interaction buttons for "Like", "Add to", and "Share", along with a view count of "101 views" and "0 likes, 0 dislikes". The video description at the bottom reads: "Celiac disease is a sensitivity to gluten, a protein found in wheat, rye, barley,".

## RTFSSM Evaluation

- ▶ Facebook Groups  
Group members, number & content of posts,  
poll responses, face to face event attendance
  
- ▶ Twitter Analytics
  
- ▶ SurveyMonkey
  
- ▶ Focus group

## References

1. Goble, L.A. The impact of a child's chronic illness on fathers. *Issues in Comprehensive Pediatric Nursing*, 27:153-262.  
doi: 10.1080/01460860490497787
  
2. Centers for Disease Control and Prevention, 2010. Health Communicator's Social Media Toolkit. Retrieved January 27, 2011 from [http://www.cdc.gov/healthcommunication/ToolsTemplates/SocialMediaToolkit\\_BM.pdf](http://www.cdc.gov/healthcommunication/ToolsTemplates/SocialMediaToolkit_BM.pdf)

**Thank You!**

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