Kintalk.org
Empowering Families Through Communication and Education

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The Birth of Kintalk

- Genetic information needed to come out of the dark and into the light.
- Patients need an easy way to electronically **store**, **communicate** and **share** their genetic information.
- Social media and email are powerful **communication tools.**
- Patients need access to **accurate** and **appropriate** educational materials and resources.

Importance of sharing genetic information

Fam Cancer. 2014 Apr 27. [Epub ahead of print]

Evaluating the utilization of educational materials in communicating about Lynch syndrome to at-risk relatives.

Dilzell K[1], Kingham K, Ormond K, Ladabaum U.

⊕ **Author information**

Abstract

Facilitating family communication about Lynch syndrome is a public health priority since following appropriate screening guidelines can decrease morbidity and mortality. The aims of this study were to (1) ascertain what educational materials individuals with Lynch syndrome provide to at-risk relatives, and (2) identify relationships between receiving educational materials and pursuing clinical follow-up. Seventy-four participants, recruited from the Stanford Cancer Institute and a support group, completed an online questionnaire; 50 were first to be diagnosed with a Lynch syndrome mutation in their family (probands) and 24 were first or second-degree relatives. Probands reported informing 88 % (184/209) of first-degree relatives and 64 % (161/252) of second-degree relatives of the mutation. Probands shared their genetic counseling note with 53 % of relatives; other resources, including family letters, personal notes, testing laboratory information, online resources, support group information, and genetics referrals, were given to 33 % or fewer relatives. Probands reported that female relatives ($p = 0.028$) and first-degree relatives ($p \leq 0.001$) were more likely to be given materials. Relatives who received an educational material were more likely to follow up with a clinician (74 vs 22 %, $p \leq 0.001$) and attend a genetic counseling appointment (43 vs 16 %, $p \leq 0.001$). First-degree relatives who received an educational material were more likely to have undergone genetic testing (51 vs 19 %, $p = 0.012$) and cancer screening (69 vs 29 %, $p = 0.001$). Facilitating information transmission in families with Lynch syndrome using educational materials may play a role in informed clinical decision-making and cascade screening of at-risk relatives.

PMID: 24770865 [PubMed - as supplied by publisher]

"Empowering Families Through Communication and Education"

Kintalk

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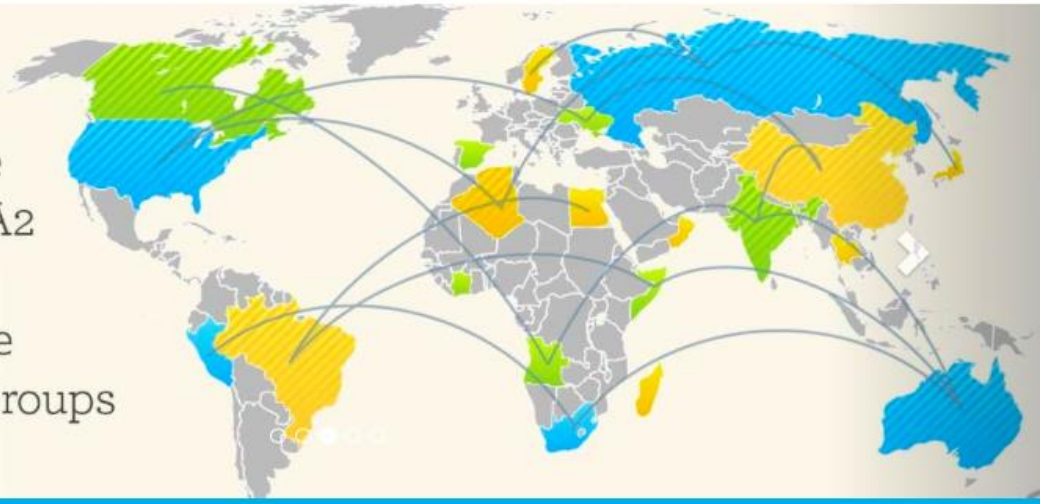


Our Mission: Providing Education and Tools to Share Genetic Information with Family Members

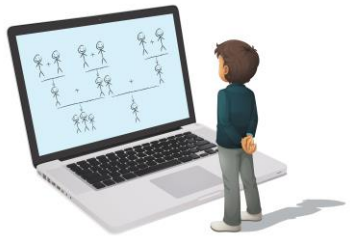
Helping Families Now:

We help families by providing free education, support and help finding early

Goals of Kintalk

- Kintalk was created to:
  - **Electronically** privately & securely **share** genetic information with **family members**
  - **Provide** individuals and their families **educational information** about BRCA and Lynch Syndrome (LS) via
    - Podcasts, Breaking News, Clinical Trials, Resources, Screening Guidelines, ect.
  - **Connect** people with BRCA mutations and LS through **moderated** interactive **discussions**

Sharing Your Genetic Information



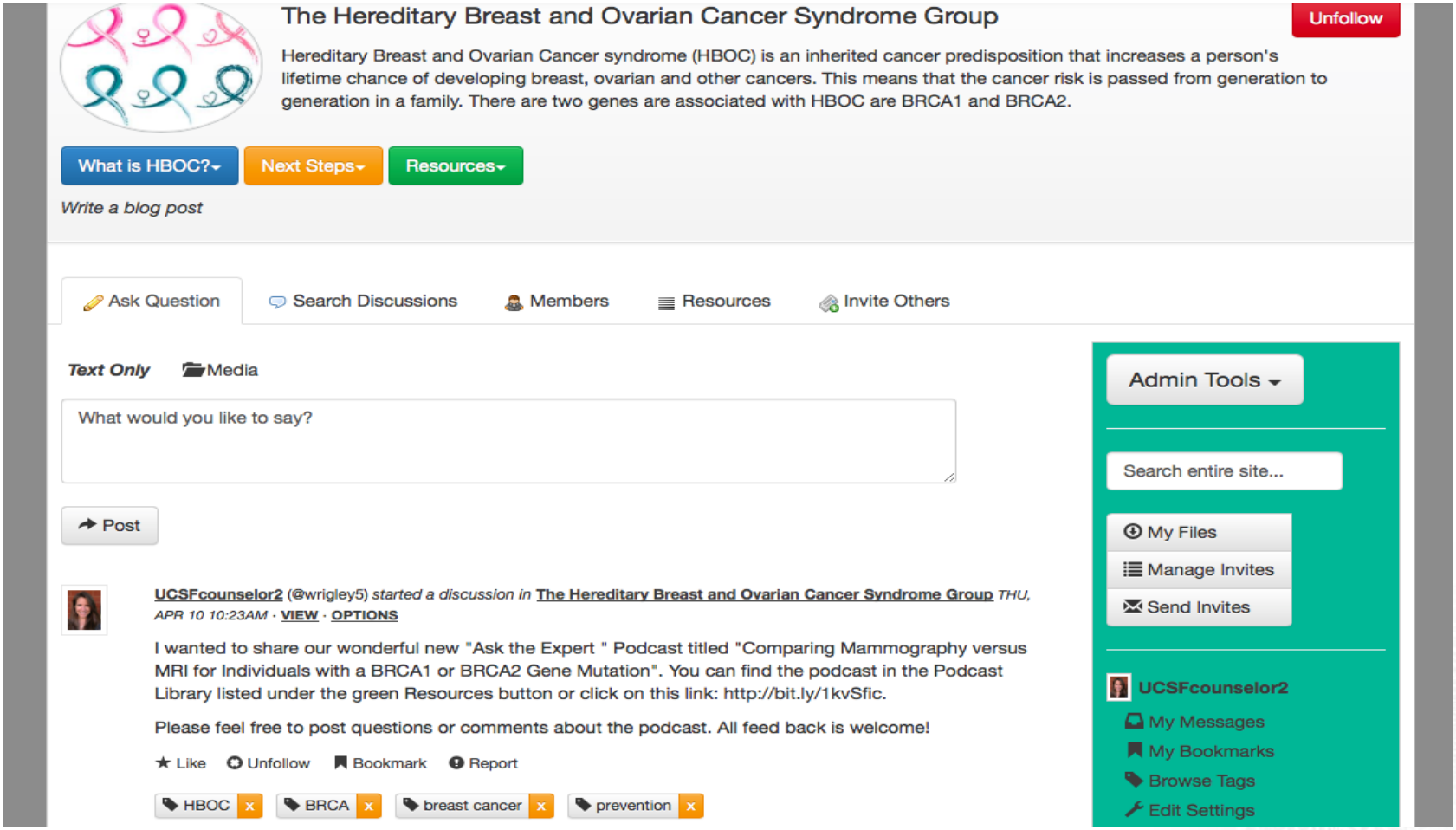
- Members upload their private genetic information
  - Pedigrees, test results, family letters, screening recommendations, etc.
- Members send secure invites to family members to view their information
  - Can be done completely anonymously
  - Manage invites
  - Family members have access to information and all education materials on Kintalk to facilitate their decision making

Approved by UCSF Privacy and Legal

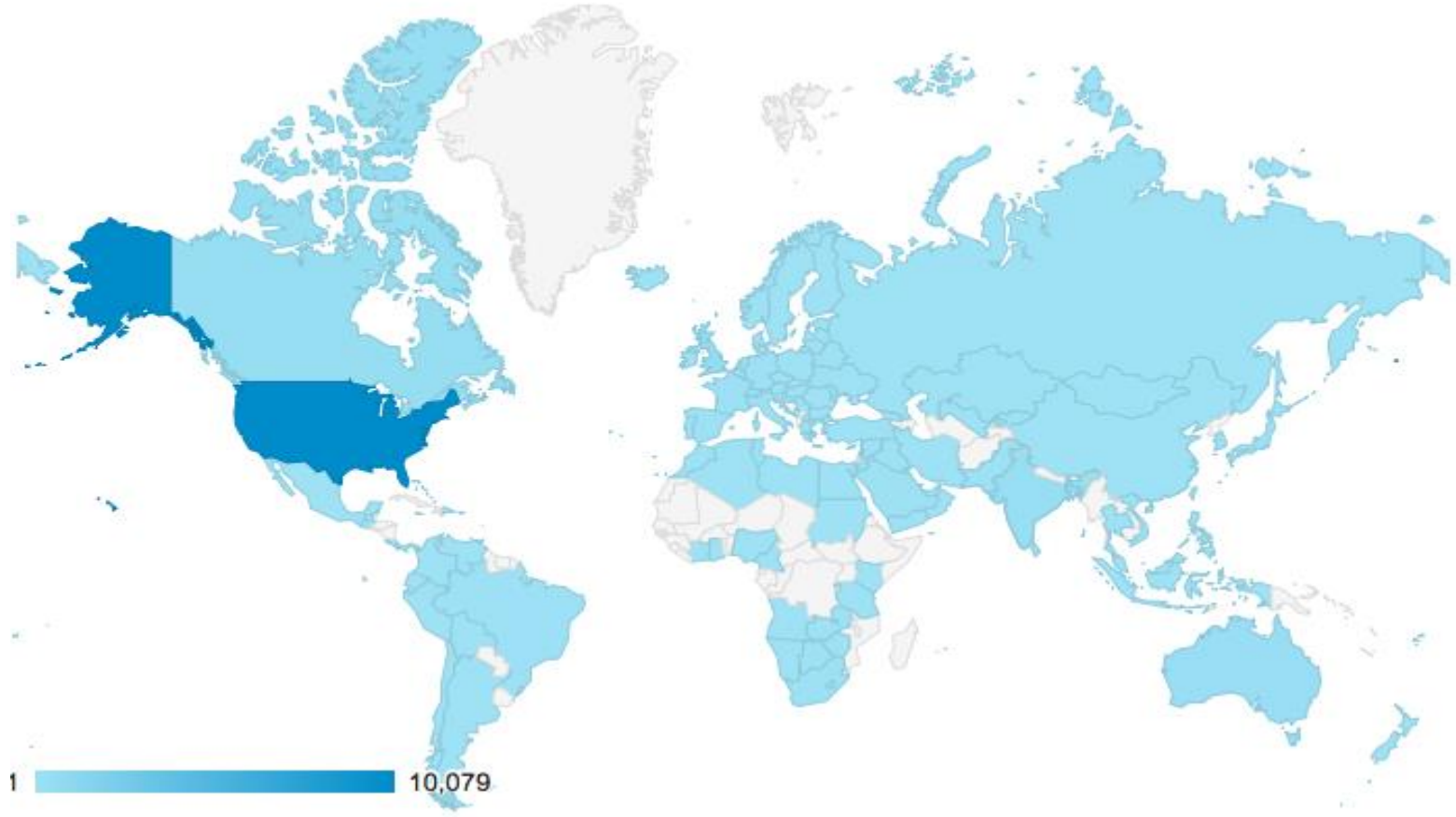
Other Kintalk Functions and Features

- LS, HBOC & cancer news, clinical trials & articles
- Podcasts by UCSF specialists
- Twitter: @KintalkUCSF
- You Tube Channel: Kintalk UCSF
- Moderated Q & A forum
- Resources including
  - Basics of genetics and heredity
  - How to find a genetic counselor
  - Information on other hereditary cancer syndromes
  - NCCN screening recommendations

Kintalk HBOC Community



Demographics of Individuals Accessing Kintalk



Kintalk Member Feedback

- "What an absolutely wonderful resource for those of us with Lynch syndrome and our families. A big thanks to UCSF for caring and instituting a great communication resource for us."
- "I was so relieved when I found this site and I realized there were others with Lynch Syndrome like me."

The Future of Kintalk

- Continue educating families and clinicians about Kintalk
- Creating more educational content
- Expand Kintalk to other hereditary conditions
- Development
  - Collaborations with other medical centers
    - Email megan.myers@ucsf.edu if interested
  - EMR integration

Kintalk Live

www.kintalk.org