

# **Building a Family Network**

## **GHC/GHRI/UW**

GHC = Kaiser Permanente of Washington

GHRI = Kaiser Permanente Washington Health  
Research Institute

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February 2, 2017

# Family Network

- Providing information to family members at risk for their own health care
- Sharing information because of looking for support
  - Correlated with the severity of disease?
- Barriers of sharing genetic information
  - Family dynamics
  - HIPAA vs. Duty to Warn

# Three families from eMERGEII with PGRNSeq actionable variants

## Molecular Genetics & Genomic Medicine

Open Access

ORIGINAL ARTICLE

### Building a family network from genetic testing

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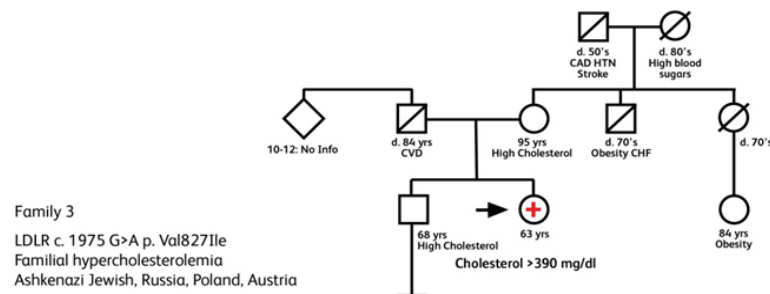
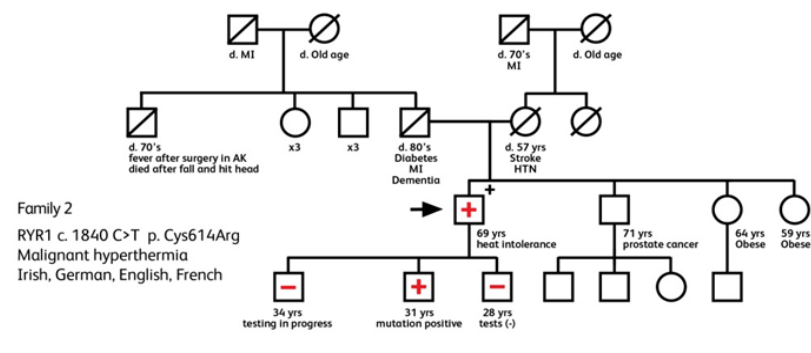
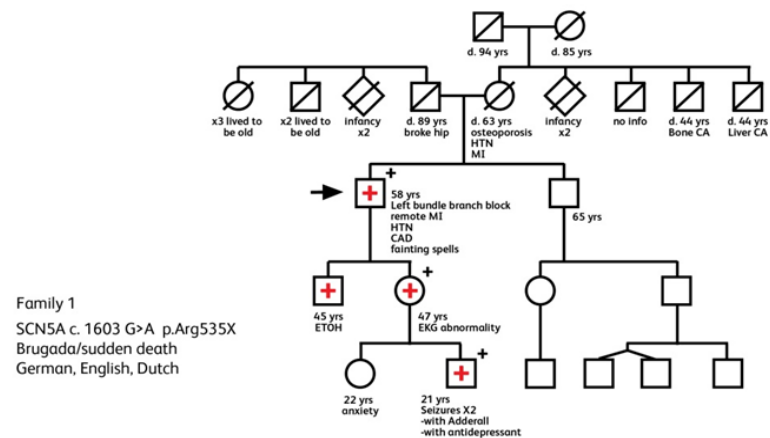
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# eMERGE Supplement: Family Network Approach to Assess the Trickle-Down Effect of Genetic Testing

**Specific Aim: To explore the feasibility of health systems-led identification and communication with family members of eMERGE participants**

- Patients to be included are members of GHC/KPW and enrolled in eMERGE
- GHC/KPW will be returning pathogenic, likely pathogenic, VUS for CRC, and negative results to eMERGE participants
- GHC/KPW is an integrated healthcare system



Nora Henrikson, PhD

# To explore social, ethical and legal feasibility:

We will conduct semi-structured interviews with approximately 20 eMERGE participants before results have returned with:

- Topics:
  - Family definition
  - Preferred role (if any) in GHC/KPW for sharing actionable results with likely affected family members who are also GHC/KPW members
    - GHC/KPW duty to contact relatives directly with the proband's consent
    - Use of EMR for sharing information, particularly between providers
    - Special considerations for minors
  - Hypothetical scenarios: clinical vignettes (CRC and Marfan syndrome) followed by questionnaire

# Building a Family Structure

- We will also collect contact information for relatives identified by each participant
  - We will attempt to identify relatives based on first name/last name/DOB provided by eMERGE participant
  - We will NOT access relatives' EMR or contact relatives directly

Currently questionnaire and vignettes are at IRB for approval

# Legal Ramifications

- In contact with GHC/KPW legal consultants regarding the process within our institution
- Consultation with Bob Wildin, MD at NHGRI regarding Family History Tool
- In Process: Assembling a team of legal experts from the eMERGE sites to address issues including duty to warn vs. HIPAA

# Ongoing Work

- Family Talk trial to improve CRC genetic results communication headed by Deb Bowen.
- Development of DOT phrases to be used in all eMERGE return of results appointments for consistent collection of information
- Exploration of family network development in other patient populations with a genetic diagnosis
- Development of eMERGE wide Family Network project, in conjunction with ROR



# eMERGE KPW/KWHRI/UW

## **Family Network Supplement Team at Kaiser Washington Health and U. Washington:**

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- Funded by a supplement to the Electronic Medical Records and Genomics (eMERGE) Network, Phase III (NHGRI U01 HG008657)

## The rest of the Seattle team:

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