



# Molecular genetic test orders

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# Genetic testing in Washington and the Pacific Northwest

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- Snapshot of testing in 2001/2002
  - What tests are being ordered?
  - Where are tests being performed?
  - How is the genetic testing laboratory chosen?



# Washington State database

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- WA Medical Test Site (MTS) Program
  - CLIA-exempt state program
  - More detail about genetic tests than CLIA database
    - Molecular
    - Biochemical
    - Cytogenetic
    - Maternal serum AFP



# Genetic testing in Washington

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- 13 of 716 moderate/high complexity labs (1.8%) perform genetic testing
  - 12/13 molecular
    - 6/13 cytogenetic
    - 2/13 biochemical



# Genetic testing in Washington

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- 6 research labs
  - Providing results for patient care
- 4 hospitals (university & children's)
- 2 independent labs (1 hospital-based)
- 1 State public health lab (newborn screening)
- 85% are accredited by private organization
  - CAP, AABB, ASHI



# Genetic testing in Washington

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- 11 of 716 moderate/high complexity labs (1.5%) perform maternal serum AFP
- Genetic testing accounts for 0.4% of total volume of testing in Washington's moderate/high complexity labs
- 0.37% of which is newborn screening



# Data from Pacific NW network

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- Lab Medicine Sentinel Monitoring Network
  - Voluntary participation by 600+ laboratories
    - Waived, PPMP, moderate, high complexity
    - POL, hospital, independent labs
    - Alaska, Idaho, Oregon, Washington
  - Questionnaire sent to 330 moderate & high complexity labs in January 2002
  - 204 respondents - Genetic testing orders



# Questionnaire respondents

	Questionnaire respondents N = 204	All network participants N = 330	All labs in Pacific NW N = 1539
AK (%)	9	9	6
ID (%)	19	19	16
OR (%)	22	22	32
WA (%)	50	49	46





# Questionnaire respondents

	Questionnaire respondents N = 204	All network participants N = 330	All labs in Pacific NW N = 1539
Urban/Rural (%)	54/46	56/44	68/32
POL/Hosp/IL (%)	59/31/9	59/31/10	73/17/10
Accredited (%)	32	33	30



# Network questionnaire results

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- 53% of respondents handled orders for molecular genetic tests in previous 3 months (October - December 2001)
  - 66% of hospitals
  - 58% of independent (reference) labs
  - 46% of physician office labs



# What tests are most commonly ordered?

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- 1) Factor V Leiden Thrombophilia
- 2) Fragile X Syndrome
- 3) Hemochromatosis
- 4) Cystic Fibrosis
- 5) Hemoglobin S
- 6) BCR/ABL Translocation
- 7) BRCA-1 or BRCA-2
- 8) Huntington Disease
- 9) Prader-Willi Syndrome
- 10) Y Chromosome Detection



# On-site testing

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- 2% of the network respondents performed molecular genetic testing on-site
  - 3 independent, 1 hospital
  - All urban
  - All accredited



# Send-out testing

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- 62% sent orders to their reference lab, who in turn decided where the test would be performed
- 7% sent orders directly to the genetic testing lab
- 31% did some combination of these



# How is the genetic testing laboratory chosen?

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- Of 95 responses:
  - 39 % Information from reference lab (37%) or Internet resource about reference labs (2%)
  - 39 % Information from health care provider
    - Genetic counselor (12%)
    - Patient's provider (12%)
    - Medical geneticist (10%)
    - Neurologist, oncologist, pathologist, etc (5%)
  - 8 % Do not know
  - 4 % Mandated by managed care contract agreement



# Where does testing go?

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- 52% stays within the Pacific NW region
- 48% is sent out of the region
  - 15% to large national reference labs
    - Quest/Nichols Institute - California
    - Lab Corp - North Carolina
  - 33% to other genetic testing labs