
Heartland Regional Genetics and Newborn Screening Collaborative Annual Report 2007

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Questions to be addressed

- ✓ How did we get here? (Shuger)
 - ✓ What is our mission and vision? (Mulvihill)
 - ✓ How can a regional collaborative have a significant impact? (Watson)
 - What is the role of the Regional Coordinating Center (RCC)?
 - What is our strategy for achieving the major goals?
 - What have we accomplished?
 - Where does the money go?
 - Why did we readjust our organizational structure?
 - What are we doing this year?
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What is the role of the Regional Coordinating Center?

- Facilitate regional communication
 - Website
 - Meetings
 - Listserve
 - Disseminate information
 - Facilitate regional collaboration
 - Pilot project program
 - Work groups
 - Link region and states to national opportunities
 - Link public health, genetics, and other relevant programs
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Website <http://heartland.ouhsc.edu>

September 1, 2006 – August 29, 2007

- Transitioned from University of OK designer to private designer, Kinetic Communications.
 - Unique visitors:
 - 3,192
 - average **8** unique visitors each day
 - average **76** visits per day
 - Visitors from 54 countries (US, China, Canada, Czech Republic, and Japan)
 - Calendar is the most frequently visited page
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Referrers of unique visitors

■ Google	1,101	■ UTHSCSA.edu	125
■ Yahoo.com	113	■ NCCRCG.org	40
■ MSN.com	102	■ Genetests.org	34
■ Live.com	59		
■ AOL	15		

Family Health History

<http://www.heartlandfamilyhistory.org/>

- Product of Education Committee
 - 5 months of data (March – Aug 2007)
 - 62 unique users; US and Australia
 - Most visited page is for family history tools
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Website Plans

2007-2008

- Soliciting bids to move all components (hosting, design, family health history) to a single private company
 - Educational mission—consumers of genetic services and primary care
 - Communication and working tool for collaborative members
 - Venue for Heartland products
 - Feedback is welcomed!
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Annual Meetings



- February 2005 St Louis 45
- October 2005 Kansas City 38
- September 2006 Omaha 74
- **September 2007 Oklahoma City 100!!!**

Disseminating Information

- Listserve
 - Topics include clinical questions
 - Announcements
 - Funding opportunities
 - Legislative bulletins
 - Group e-mail
 - State Genetics Advisory Councils
 - Newsletter***
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Strategies and Outcomes

Strategies

Key stakeholder involvement

Communication infrastructure

Regional Plan

Pilot project program

All states have a working state
plan in place

State infrastructure

Outcomes

All 8 states involved

Website, Listserve, Meetings, State
Genetics Coordinators

Completed 2006

Build collaboration and seed projects;
National model

KS and ND state plans

Scholarship to Sarah Lawrence
College Genomics Certificate
program

Stakeholders

Heartland Regional Council on Genetics

February 2005 – September 2007

(Total council membership = 65; 80 total slots (81%) filled)

<u>Stakeholder Group</u>	<u>N</u>	<u>Inactive</u>	<u>(%)</u>	<u>New</u>
■ Academia	21	5	(32)	(10)
■ Public health	20	0	(31)	(65)
■ Advocacy	9	0	(14)	(15)
■ Private	10	3	(15)	
□ Clinical	7			
□ Industry	3			
■ Other Specialists	6	4	(9)	
■ Laboratory (not PH)	2	0	(3)	
■ Primary Care	2	2	(3)	(10)

Pilot Projects

- 3 cycles with 13 awarded projects (2 were cancelled)
 - Received 100% of reviews
 - Reviewers are mixture of content experts, advocates, external, Genetic Services Branch
 - Major activity of the Research Committee
 - States
 - MO: 6
 - OK: 3
 - IA: 2
 - KS: 2
 - AR: 1
 - NE: 1
 - ND: 1
 - SD: 1
 - Topics
 - Newborn Screening: 6
 - Education: 5
 - Clinical Genetics: 3
 - Access: 2
 - Public Health Genetics: 1
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Accomplishments

- NBS DVD/Videos
 - NBS blood spot retention paper
 - Clinical and Laboratory Standards Institute guidelines for newborn screening follow-up
 - Advocacy training
 - Clinical services directory and link to GeneTests
 - Family health history education
 - Telemedicine capacity and guide
 - DNA day toolkit
 - MS/MS data collection and wet-bench workshops
 - Inter-regional collaboration
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Where does the money go?

- Year 1 (8 months): \$288,334
- Year 2: \$394,000
- Year 3: \$394,000
- Year 4: \$418,673

Category	Includes	Percent of budget requested
Regional Coordinating Center expenses	Salaries, teleconference calls, printing, websites	37%
Projects	Line item & pilot projects	29%
Annual meeting	Lodging, travel for council members, honoraria and participant expenses, hotel costs	11%
Indirect Cost Rate		23%

Prioritizing Activities

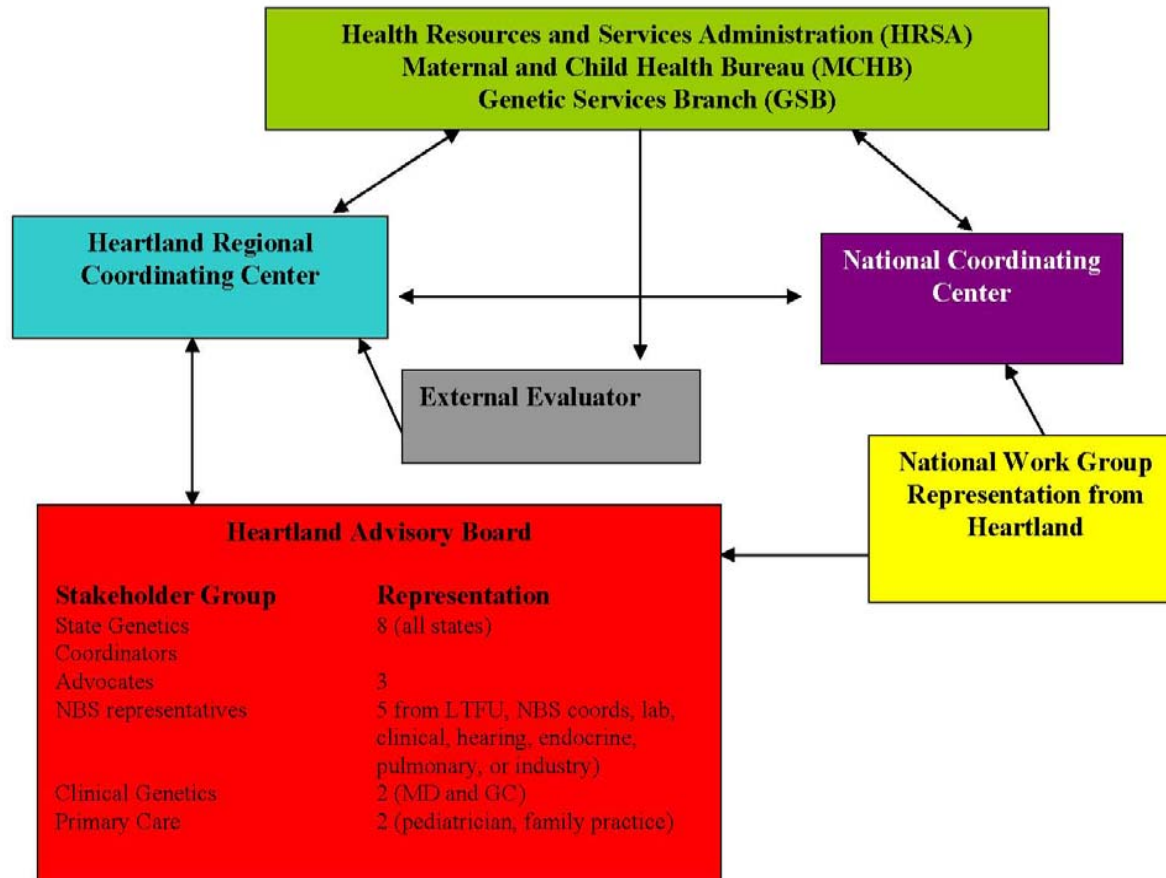
- Low vs. high; new vs. underway
 - Executive committee reviewed and discussed
 - This year:
 - PCP educational project (Education WG)
 - Health passport (RCC)
 - Genetics report card (RCC)
 - Disaster preparedness (NBS WG)
 - **Medical home (Clinical Services WG)
 - **Advocacy
 - Work groups' tasks (action and planning)
 - Next fiscal year: **PLAN NOW!!!**
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Organizational Structure

- Rationale for change
 - Genetic Services Branch suggestion
 - Involves active participants
 - Increase productivity and effectiveness
 - Confusion about the advisory body (e.g., council or Exec Cmte)
 - Smaller advisory group
 - Major changes
 - Committee become Work Groups
 - Core membership for Work Groups
 - Advisory Board membership
 - Regional Coordinating Center facilitate Work Groups
 - Refer to organizational chart
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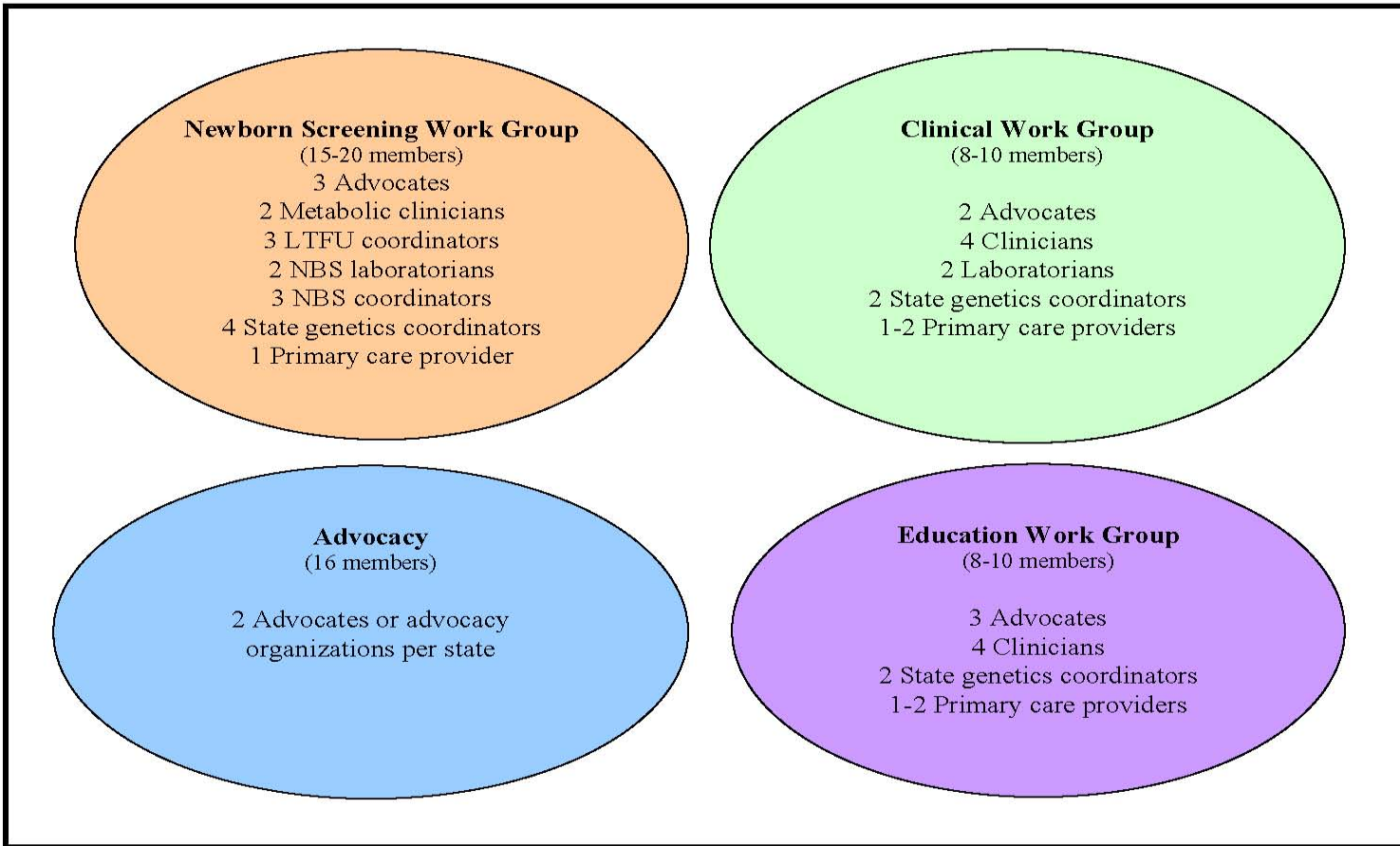
Organizational Chart

September 2007



Organizational Chart

September 2007



Next steps

- Work groups (Advocacy, Education, Clinical Services, and Newborn Screening) will identify core membership
 - Key stakeholder groups will be asked to identify leadership for Advisory Board
 - Work groups will meet by teleconference call every 4-6 weeks
 - Advisory Board will meet monthly by teleconference call
 - Regional Coordinating Center seeks nominations from region for national work groups
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Acknowledgments

- **Regional Coordinating Center Team:**

- Mulvihill—PI
- Kyna Byerly—Assistant project manager (Clinical Services and Advocacy, website, and conference)
- Sharon Vaz—PRN (Education)

- **Committee Chairs:**

- Education: Kimberly Noble Piper (IA)
 - Clinical Services: Blaine Bendure (AR) and Quinn Stein (SD); Melissa Craft
 - Policy: Larry Weatherford (OK)
 - Laboratory: Fred Schaefer (OK)
 - Advocacy: Teresa Willige (OK) and Jeanne Egger (NE)
 - Newborn Screening: Sara Copeland (IA)
 - Research: Merlin Butler (MO)
 - State Genetics Coordinators
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Acknowledgments

- State Genetics Coordinators
 - My colleagues
 - My students
 - Project Managers in the other regions
 - Cheryl McIntosh
 - Gene Hallford
 - Matt Grim
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Isabella Stringer

2006-2007

- Isabella, daughter of Mike and Michelle and sister of Jackson
 - Diagnosed with lissencephaly at 6 weeks of age
 - This spring, Isabella passed away in her home with her family present
 - Advocate for disability rights and served on the Heartland Advocacy Work Group
 - Michelle and Sharon advocated for a play ground for children with physical disabilities in Norman, OK new city park
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