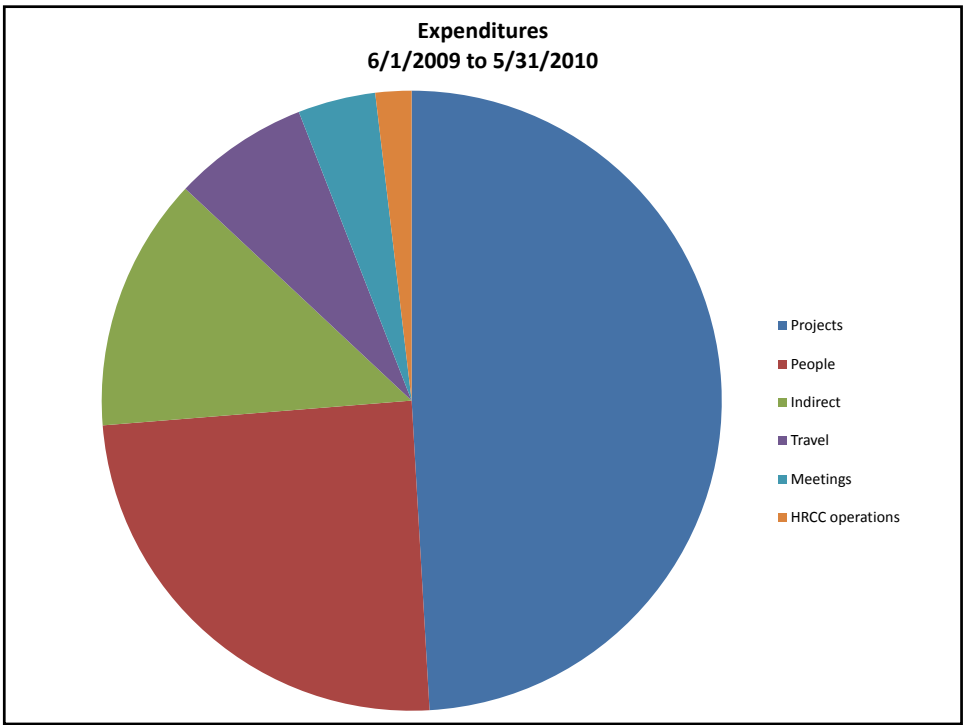





HRCC Report


What the HRCC is in fact doing





Projects

- Genetic Services Assessment
 - Develop and pilot an assessment tool for genetic services
 - Collaborators and stakeholders
 - Genetic Alliance, HRSA/GSB, clinicians, ACMG, NSGC, CDC, other RCCs, RAND Corp, NNSGRC, AHRQ
- Tele-genetics
 - Manual
 - AR-KS clinics



Projects

- Transition
 - HRSA work group
 - Collaborative with D70s
- Emergency Preparedness
 - Laboratory and clinical services



Projects

- Newborn Screening
 - Workgroup eval of SCIDs in region
- Long-term follow up
 - Effective follow up (HRSA)
 - Participation in Region IV project



Projects

- Web-based “just in time” modules
 - 2 completed
 - 2 in process
- EMR
 - MO project evaluating data linkage
 - Data linkage system evaluation
- Education
 - Genetics education for nurses




Collaborations

- Individual state programs
 - State genetic plans
- Lay advocates
 - Financial resource guide
 - Position statements on NBS and blood spots




Collaborations

- Genetic Alliance
 - Advocate Partners Program
 - GSA
 - NBS Clearing house
 - Cong. Conditions project



Collaborations

- NCC
- Other RCs



Administration

- Advisory board structure
- Small grants / pilot projects
 - Current projects (began 06/01/10)
 - PKU camp, I-library
 - Next RFP
 - Release October 2010
 - Funds to start 06/01/11



Administration

- Work groups
 - Standing
 - Education, clinical services, NBS, advocacy
 - Ad hoc
 - Transition
 - EDHI
- Evaluation (B. Jackson)



Consultants

| NAME | PROJECT |
|----------------------------|--------------------------------|
| Ann Chou and Johann Chanin | Genetic Systems Assessment |
| Barbara Jackson | Heartland Evaluator |
| Mary Ann Coffman | RCC Project Coordinator |
| Sandy Daack-Hirsch | Genetics Curriculum for Nurses |



Dissemination of our work

- 4 poster presentations



Next steps

- Evaluate current work
 - Continue priority projects
 - Phase out lower yield efforts
- Identify new high impact efforts
- Prepare for competitive renewal
 - Changes in structure?
 - Changes in focus?