A Comprehensive System of Providing Follow-Up Newborn Screening Services for Hemoglobinopathies in Hawaii

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Background Information

- Began screening for hemoglobinopathies in 1997

- Most common screen positive condition
  - Alpha thalassemia = 1 in 42

- Families should receive:
  - Confirmatory testing
  - Genetic counseling
  - Appropriate medical management
No protocol for follow-up

- Pediatricians used best judgment
  - Provided follow-up themselves
  - Referred to specialist
  - Did nothing

Hemoglobinopathy Clinic established in 2006

- Part of the pediatric genetics clinic
Hemoglobinopathy Clinic

- Collaborative partnership:
  - Genetic counselors from DOH Genetics Program
  - Funding from NBS Program for 0.5 FTE administrative assistant
  - Medical geneticist from pediatrics clinic

- NBS Program sends clinic contact information with every screen positive result
Genetic Testing

- Genetic testing for:
  - Newborn confirms the NBS result
  - Parents for recurrence risks

- Some insurance would not cover testing
  - Affected family’s willingness to get testing
  - Difficult to provide good follow-up
  - Caused a health disparity—discriminatory?

- **Solution:** NBS Program contracted for testing
  - Guaranteed samples for lab
  - Families had testing cost covered
Genetic Testing

- Covered newborn and parents for:
  - DNA testing for alpha thalassemia
  - CBC
  - Blood draw

- Retroactive
  - Also covered previous newborns that screened positive for alpha thalassemia

- Significantly increased number of families following through with testing
Telemedicine

- Hawaii is made up of eight main islands
  - Genetic services only on Oahu
  - Neighbor island families must fly to Oahu
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- Developed telemedicine on five sites
  - Began June 2006
  - Increases access to services
Telemedicine

- Partnership between:
  - University of Hawaii → Honolulu equipment and tech support
  - Department of Health → Neighbor island equipment and family support
  - Hemoglobinopathy Clinic → specialists

- Families offered telemedicine or Honolulu clinic appointment
Data

- 54 patients evaluated
- Increased uptake over the years
  - Increased exposure
  - Increased comfort level
- Primarily for alpha thalassemia
  - HbE, SC, unknown hemoglobinopathies
  - Follow-up general genetics patients
Data

- **Satisfaction surveys:**
  - Families
  - Specialists
  - Onsite facilitator
  - Referring provider

- **Data on:**
  - Reimbursement
  - Provider time
Survey Data

- Data is overwhelmingly positive
  - Families prefer the telemedicine consult
  - Families are very comfortable with the method of communication
  - Families were “very confident” in the quality of care provided via telemedicine
  - Geneticist, family, onsite facilitator, and referring physician would strongly recommend telemedicine to other families
Reimbursement

- Reimbursement tracked from beginning
  - Claim submitted with modifier code

- Has improved over time
  - 2006-early 2007 = usually denied
  - Mid-2007 = reimbursed poorly
  - 2009 = reimbursed at equivalent rate

- Rate varies by insurance type and ICD-9 code
Reimbursement

- Current Challenge: Place of service
  - Honolulu-based geneticist at University of Hawaii
  - Place of service not recognized
  - Location of geneticist should not be an issue—that’s the point of telemedicine!

- Working with the geneticist and hospital to find a solution
Personnel Time

- Geneticist and genetic counselor time:
  - Prepping – longer for genetic counselor
  - During
  - Following-up
  - Traveling

- Onsite facilitator
  - Coordinating – extra time than for in-person clinic
  - During
  - Following-up

- Project assistant
  - Coordinating
Personnel Time

- More time on the front end
  - Coordinating the clinic
  - Prepping for the clinic

- More time than for in-person clinic

- Less time than for outreach clinic
  - Less travel time for specialists
Other Costs

- Line charges or equipment fees
  - Free through University of Hawaii and Department of Health

- Room rental or facility fees
  - Free through University of Hawaii and Department of Health
Lessons Learned

- Current reimbursement does not cover costs of a telemedicine clinic

- Public-private partnerships:
  - Clinic success
  - Testing success
  - Telemedicine success
Take Home Messages

- Telehealth is a viable method to provide genetic evaluation and counseling for hemoglobinopathies

- Families and providers are very satisfied and comfortable with telehealth

- Successful programs will need public-private partnerships for sustainability
Mahalo to Those that Make it Happen

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