



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



Background Information

- 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

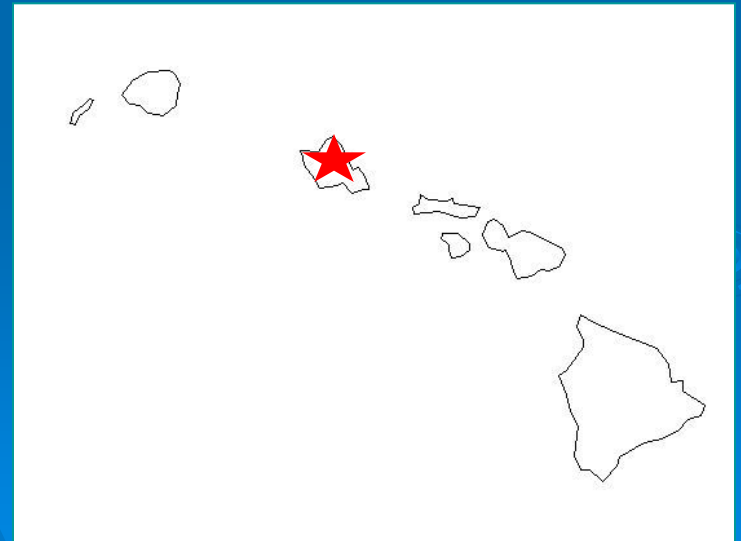
- Genetic testing for:
 - Newborn  confirms the NBS result
 - Parents  for recurrence risks
- Some insurance would not cover testing
 - Affected family's willingness to get testing
 - Difficult to provide good follow-up
 - Caused a health disparity—discriminatory?
- **Solution:** NBS Program contracted 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

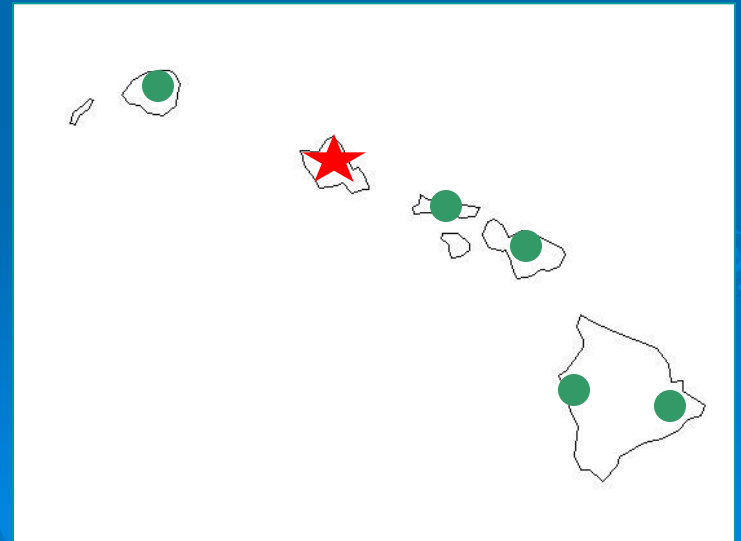
Telemedicine

- Hawaii is made up of eight main islands
 - Genetic services only on Oahu
 - Neighbor island families must fly to Oahu



Telemedicine

- Hawaii is made up of eight main islands
 - Genetic services only on Oahu
 - Neighbor island families must fly to Oahu
- 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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