"Every Child Deserves A Medical Home"

What is a Medical Home?

A Medical Home is not a building, house, or hospital, but rather an integrated and trusted partnership to provide health care services in a high quality, cost effective manner.

Pediatric health care professionals and parents act as partners in a Medical Home to identify and access all medical and non-medical services needed to help children and their families achieve maximum potential.

Medical Home promotes community-based primary care that is accessible, comprehensive, continuous, and coordinated, delivered in family-centered, compassionate, and culturally effective ways.

Medical Home Works! aims to increase capacity in developing community-based partnerships between families, physicians, and community agencies to address the needs of all children, particularly children with special needs. This Medical Home Family Stories video series provides brief family stories to stimulate discussion, learning, and implementation of Medical Home strategies that work.

DVD Video: Bernadette's Story (15 min.)
DVD ROM Companion Materials:
- **Family Inserts**
- **AAP Resources**
- **DVD Evaluation**
- **Key Internet Links**

Bernadette's Story Production Team Sends Special Thanks to:
The Galano Family, Jane Kato, Suzanne Nelson, Pat Pablo, Dely Sasaki, and Shayne Tokita.

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Kenn Saruwatari, MD, FAAP **Calvin C. J. Sia, MD, FAAP**
Leolinda Parlin **Patricia Heu, MD, FAAP**
Josie Woll **Kathryn Sthay**

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For information on **Medical Home Works!** and the **Medical Home Family Stories** contact:
Sharon Taba, Project Director
Medical Home Works!
c/o Department of Pediatrics
John A. Burns School of Medicine
University of Hawai'i at Manoa
1319 Punahou Street, Seventh Floor
Honolulu, Hawai'i 96826
Telephone: 808.983.8387
Email contact: Kathryn Sthay, Executive Director AAP Hawai'i Chapter
<aaphawaii@verizon.net>

Related Resources:
- www.medicalhomeinfo.com-Website for the National Center of Medical Home Initiatives for Children with Special Needs
- www.aap.org-Website for American Academy of Pediatrics, see Department of Community Pediatrics
- www.mchb.gov-Website for U.S. Maternal and Child Health Bureau, Division for Children with Special Health Care Needs

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Video Guide
Medical Home Works!
presents
Medical Home Family Stories

Bernadette's Story

Spotlighting community-based, family-centered, comprehensive, coordinated, collaborative care

"Every Child Deserves A Medical Home"

Developed by:
Kenn Saruwatari, MD, FAAP, Sharon Taba, MEd, Lynn B. Wilson, PhD
Medical Home Works!, c/o Department of Pediatrics
1319 Punahou Street, Seventh Floor, Honolulu, Hawai'i, 96826
Tel: 808.983.8387

DVD Video & DVD ROM

Bernadette Galano

Bernadette is twelve years old. Her parents, Bina and Fami, immigrated from the Philippines before she was born and now live on Kauai, Hawai'i. Born extremely premature, she lived her first three years at a tertiary care facility in Honolulu. Bernadette's transitioning from hospital to home and to coordinated community-based services brought measurable improvement.

Bernadette has made great strides in school; consistent physical therapy has enabled her to begin walking, far surpassing original expectations surrounding her health, learning achievements, and social integration.

Principal Medical Home Partners

- Parents: Bina and Fami Galano
- Primary Care Physician: Suzanne Nelson, MD, FAAP Pediatrician
- Public Health Nurse: Pat Pablo, RN
- School Health Nurse: Jane Kato, RN
- Medical Specialists: PICU Intensivist, Neonatologist

Dr's Notes

- Extreme prematurity: 27 weeks
- Multiple complications: hypotonia, tracheostomy, supplemental oxygen, gastrostomy
- Anoxic encephalopathy: status post code blue
- Discharged from hospital at 3.5 years

Learning Objective

- Understand the roles of Medical Home partners
- Identify key community-based resources that provide health, educational, and social supports for the child's optimal development
- Describe Medical Home aspects of transition from hospital to home, from home to school.

Learning Points Suggested by Physicians

- **Children who are medically fragile are increasingly cared for in their home communities.** More and more, children who are medically fragile are able to leave tertiary care facilities to live with their families due to: 1) technological advances in equipment (more equipment is now smaller in size and transportable), and 2) an increase of coordinated services available in children's home communities.

- **Children who are medically fragile can thrive when cared for by extended family with support of community-based services.** When Bernadette transitioned from hospital to home, she was reacting only to painful stimuli and had no communication. The care and support of family members, involved family friends, and staff of community agencies enabled Bernadette to stabilize, improve, and thrive at home. When primary care physicians understand the importance of identifying appropriate community-based resources to families who have children with special health care needs, children will have greater opportunities to reach their optimal health. Once Bernadette's condition stabilized, very little intervention was required by the primary care physician.

- **Subspecialists at times may initiate a Medical Home.** In the Medical Home, physicians and families partner to coordinate services to address a child's medical and non-medical needs. In Bernadette's case, she had no primary care physician while in the hospital; a subspecialist in the tertiary care facility contacted over twenty health and other professionals to meet and plan for Bernadette's transition from the hospital on the island of Oahu to her family's home on Kauai.

- **An unexpected prognosis is possible.** Few would have guessed that Bernadette's transition from hospital to home to school would result in her making great strides in expanding her skills and learning including language arts, computer, and music as well as beginning to walk.

Learning Points Suggested by Families

- **Culturally effective health services can contribute to developing trust among Medical Home partners.** Immigrant families have tremendous challenges in negotiating health delivery in English, understanding complicated diagnoses, and understanding new systems of health care delivery that can result in a distrust of professional services. In Bernadette's case, health professionals were culturally effective in providing direct translation when possible, listening respectfully, asking appropriate questions, and providing support to create comprehensive coordination.

- **Care coordination requires mutual trust between families and Medical Home partners.** Care coordination with multiple representatives of community-based agencies can bring many people, sometimes for short periods of time, into the lives of families who have children with special health care needs. Care coordination becomes more effective when professionals understand the privacy a family needs and when families understand the need to open up their homes to health care partners.

- **Families' persistence is a major factor in pursuing their child's optimal health outcome.** When a family has the commitment to sustain their child's life whenever possible, they need the support of their Medical Home to translate this value into concrete health plans. As children who are medically fragile move through health and life transitions, families will make decisions in partnership with the Medical Home, requiring persistence on the part of the family and, for physicians, incorporating respect, keen listening, and prudent mediation along with medical expertise.