

## “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 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: Kaiyah's Story (15 min.)

DVD ROM Companion Materials:

- Family Inserts
- DVD Evaluation
- AAP Resources
- Key Internet Links

Kaiyah's Story Production Team Sends Special Thanks to:  
Lea Hocson, Arley Alani, Kay Nakamura and Suzanne Nelson

Many thanks to those who provided support and leadership to develop these resources:

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

#### Support provided by:

- U.S. Maternal and Child Health Bureau  
Division of Children with Special Health Care Needs  
(Supported in part by Project 5 H02 MC 00116-03-00,  
Title V Social Security Act, Health Resources and Services Administration,  
Department of Health and Human Services)

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

Video Production & Post Production: WEBfish Pacific, Honolulu, Hawai'i  
Graphic Design: Studio K, Kailua, Hawai'i  
Medical Home Works! © 2005 All Rights Reserved.

# home

Video Guide  
**Medical Home Works!**  
presents

Medical Home Family Stories

## Kaiyah'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

# medica

## Kaiyah Alani

Kaiyah is three years old. Born healthy and full-term, on her fourth day she suddenly presented with severe jaundice that led to severe brain damage and accompanying complications. Her family lives on Kauai, Hawaii, and combines Native Hawaiian and Portuguese descent. Her parents, Lea and Arley, are domestic partners living with Kaiyah's younger sister and supported by other family members including Lea's mother and Kaiyah's older half brother. Care coordination and access to services became major issues when Kaiyah returned to Kauai from Honolulu six months after her birth.

### Principal Medical Home Partners

- Parents: Lea Hocson and Arley Alani
- Primary Care Physician: Suzanne Nelson, MD, Pediatrician
- Title V Care Coordinator: Kay Nakamura, MSW
- Medical Specialists: Geneticist, Endocrinologist, Gastroenterologist

### Dr's Notes

- Hyperbilirubinemia led to kernicteris, severe brain damage
- Uses oxygen, tracheostomy, and gastrostomy
- Requires suctioning

### Learning Objective

- Understand the roles of Medical Home partners
- Describe the skills needed for the parent as care coordinator
- Analyze strategies for implementing comprehensive and continuous care
- Determine access to relevant services for the child with special health care needs



### Learning Points Suggested by Physicians

- **Roles in care coordination commonly shift over time.** The situation with families can sometimes change dramatically in a short time (insurance coverage, changes in family configuration and support, etc.). A child's short and long-term outcomes will be more positive when physicians and parents work closely together through these changes to ensure continuous access to appropriate resources.
- **Transportation is a key element in accessing medical services.** Providing effective Medical Homes to children with special health care needs requires physicians to have a working knowledge of Medicaid waiver services. Physicians familiar with Medicaid requirements will provide appropriate justification for medically necessary services, such as in Kaiyah's case, transportation for one parent and a secondary companion to accompany the medically-involved child to the tertiary care facility.
- **Skilled office support contributes to a well-coordinated Medical Home.** Skilled office staff who know the child, family, and the demands of scheduling multiple subspecialty appointments can provide substantive support to physicians and families in meeting appointments efficiently, reducing unnecessary stress for Medical Home partners.
- **Parents and physicians may have different interpretations of a child's prognosis.** Physicians at times discount parents' hopes and dreams for their children with special health care needs as "unrealistic." Rather than closing the door to a parent's vision of the future, physicians can strengthen their relationship to families by further exploring the parent's hopes: What are the steps to reach their hopes and dreams?



### Learning Points Suggested by Families

- **Families as care coordinators.** Families can contribute to care coordination, particularly the "non-medical" aspects, as a natural part of the parent's role. Parents' contributions to care coordination may shift over time depending on their changing situation. The question is "who do families have to support them in care coordination?" (e.g., Title V Coordinator, Medicaid Waiver Case Manager).
- **Being a parent and care coordinator of a child with special needs will be stressful.** Families of children with special health care needs represent wide-ranging differences related to financial status, family configuration and support, ethnicity, geography, etc. Some social factors (poverty, single parent, etc.) can compound the stress within families caring for children with special needs, yet all families negotiating systems of care and education for their children commonly experience increased levels of stress.
- **Parents can play a key role in educating physicians.** Parents, especially the seasoned ones, can be the best resource finder. Physicians can rely on parents to help link other parents to resources such as the Special Parent Information Network in their state.
- **Parents can be their own best advocates.** Some parents remain reticent to speak up about their children's and families' particular needs. Parents can articulate their concerns with physicians about skilled nursing, equipment, and supplies. Parents can negotiate with employers for time off and/or amend health policy provisions to fit their needs. Parents can join with other parents to support each other and advocate together for services.
- **Politics of language.** Which of the following reflect that children come first: "children with special needs" or "special needs children"?

