



# Medical Home Newsletter

## New Medical Home Portal

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[www.medicalhomeportal.org](http://www.medicalhomeportal.org)

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### Welcome

This publication aims to support health care providers in establishing and maintaining Medical Homes for their pediatric patients by providing useful information and tools.

**To offer comments, suggest ideas for future newsletters contact the Project Coordinator, Barbara Ward, RN [barbarward@utah.gov](mailto:barbarward@utah.gov)**

Copies of past newsletters may be found on the Medical Home Portal, found at:

[www.medicalhomeportal.org](http://www.medicalhomeportal.org)

### The new Medical Home Portal

Over the last few years the Medical Home Portal, with the support of a National Library of Medicine grant, was redesigned to improve its content, structure, and navigation. The new site is divided into five major sections (tabbed at the top of each page) that include:

- For Parents & Families
- For Physicians & Professionals
- Services & Resources
- Diagnoses & Conditions
- Newborn Disorders.

The site collaborates with eight other states to offer their own genetic resources for CSHCN, and has the potential to integrate local resource listings for any state or region.

### For Parents & Families

Here parents can learn how to find accurate and reliable information about their child's diagnosis, work with the education system, manage the transitions their child will experience, and care for their child, their siblings and themselves.

Understanding the school system and techniques for advocating for their child will help parents ask better questions when they meet with their

child's teachers, doctors, and other providers. Families can learn the school system, laws, policies, and what is available for their child in the Education subsection.

The *Utah Care Notebook* can be an important resource for families. In caring for a child with special health care needs, families get information and paperwork from many sources. The care notebook, available for download, is designed to help organize the information to assist both families and providers. Parents can download either the entire book or just the pages the family feels are pertinent.

### For Physicians & Professionals

This section provides primary care physicians and other health care professionals with information, tools, and resources to support ongoing improvement in care and outcomes for their patients, providing patient and family-centered care, and appropriate compensation for the extended or additional services involved in providing a comprehensive Medical Home.

Subsections include:

- Building a Medical Home (includes coding information)
- Screening and Prevention
- Technology Reviews
- Education and Schools
- Transition Issues

The Education subsection guides clinicians in communicating with teachers and school personnel to assure that patients receive appropriate education-related services. Details provided by clinicians will help determine 1) the patient's eligibility for Special Education, and 2) the nature of the child's special needs in the school setting. The information will be used in developing an Individualized Education Program (IEP), which may include special dietary, personal care, and medical care during school

hours. The Portal offers two forms to facilitate communication with schools, developed in collaboration with the State Office of Education. They are the “Information Release Form” and the “Form for Evaluation and Service Recommendation.”

## Services & Resources

This section compiles all the resources, services, citations, etc. from the Portal for searching. It also contains a comprehensive listing of local services (over 2300) relevant to children and families. Subsections include:

- Community and Professional Services (statewide)
- Information and Support
- Patient Education
- Tools for the Practice
- Registries and Studies
- Newsletters and Conference Calls
- Bibliography

Also compiled here are previous medical home newsletters and transcripts of the topic-oriented phone conferences offered as support to medical homes. With the transcripts are handouts related to some of the calls such as: Bullying and Autism, Vocabulary by 2, Genetic Counseling and more.

## Diagnoses & Conditions

This section includes a Diagnosis Prevalence List allowing you to see how many children with given diagnoses you could expect to find in a practice the size of yours. You will also find a growing number of Diagnosis Modules providing information, aimed at the primary care physician, about chronic conditions in children. Each Module contains:

- Description (including ICD-9 codes)
- Initial Diagnosis
- Ongoing Assessment
- Treatment & Management
- Related Issues
- FAQ
- Practice Guidelines & Helpful Articles
- Services & Other resources
- Bibliography

Full Diagnosis Modules are available for 13 diagnoses and 15 more are in various stages of development. For 6 conditions for which a full module has not been developed, the Portal offers single pages with a brief overview of the disorder and information and resources for the practitioner and family.

## Newborn Disorders

The Utah Department of Health (UDOH) screens all newborns for 37 metabolic, endocrine, and hematologic disorders. In 2007, 99.3 % of all Utah newborns (55,928 infants) were screened and 1,710 infants were followed for presumptively positive results. The medical home plays an important role in responding to positive screens. The Portal has pages on 31 specific disorders for which UDOH screens. Each page addresses: prevalence, following up on a positive screen, clinical characteristics of the disorder, management of the disorder, links to support services, and resources for information and support.

## You Can Help

The Portal is a work in progress and the Portal Team is anxious for your feedback – click on “Feedback” button at the top of any page to send a message. Did you find what you were looking for? Was it difficult to navigate? Do you have a resource that is not listed? All comments are welcome. Help us to provide comprehensive support to your Medical Home. For questions, comments, or feedback you could also contact:

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