The Barbara Bush Children's Hospital Metabolism **Program provides** specialty medical services, education and care coordination to individuals

diagnosed with Inborn Errors of Metabolism.

The Barbara Bush Children's Hospital (BBCH) Metabolism **Program provides:**

- Hospital and home visits for families as needed
- Nutrition assessment and consultations
- Initial metabolic formula as necessary
- Information
- Referrals for services
- Care coordination
- Parent-to-parent support
- Comprehensive Metabolism Clinic



About the Metabolism Clinic . . . The Barbara Bush Children's Hospital (BBCH) Metabolism Clinic . . .

Is available monthly at Maine Pediatric Specialty Group, which is located at 887 Congress

Street, in Portland, Maine

- Provides evaluation and treatment planning
- Provides information to preschools, daycares, Child Development Service agencies, public schools, etc.

Clinic visits are scheduled according to the needs of the family and to ensure appropriate therapy.

Issues that are addressed during clinic include:

- Medical and family histories
- Overall health and physical development

- Nutritional needs
- Educational needs
- Feeding strategies
- Genetic counseling
- Laboratory follow-up

Early evaluation by the Clinic Team will ensure early treatment planning.

Clinic Team members are health professionals with expertise in

the care of individuals with Inborn Errors of Metabolism. Team members include:

The Metabolism Program

provides care for patients

and their families from

infancy through

adulthood.

- Metabolic Physician
- Metabolic Dietitian
- Clinic Coordinator
- Genetic counselor
- Parent Peer
- Social Worker





- ☑ Biotinidase Deficiency
- **☑** Galactosemia
- ☑ Homocystinuria
- ✓ Maple Syrup Urine Disease (MSUD)
- ☑ Phenylketonuria (PKU)
- ☑ Fatty Acid Oxidation Disorders (MCAD, LCHAD, VLCAD, etc.)
- ✓ Organic Acid Disorders (Proprionic Acidemia, Isovaleric Acidemia, etc.)
- Amino Acid Disorders (Tyrosinemia, etc.)
- ☑ Ureacycle disorders (OTC, Citrullinemia, etc.)

Metabolic Program Contact:

Gretchen Shantar, MS, RD, LD

Metabolic Clinic Coordinator and Registered Dietitian Maine Pediatric Specialty Group: (207) 662-5522 -- phone

(207) 662-5528 -- fax

The Barbara Bush Children's Hospital Metabolism Program

Metabolic Physicians:

- Thomas Brewster, MD, Director
- Wendy Smith, MD

Metabolic Dietitian and Clinic Coordinator:

Gretchen Shantar, MS, RD, LD

Parent Peer:

> MaryAnn Gordon

Social Worker:

Michele Bednarz, LCSW

Genetic Counselors:

- ➤ Valerie Banks, MS, CGC
- Sara Ellingwood, MS, CGC



The Metabolism Program



