

We are pleased to invite you to the Region 4 Genetics Collaborative sponsored Conference, "Transitions to Adult Health Care for Individuals with Birth Defects and Genetic Conditions". This conference will address many issues and concerns related to care of adults with 'childhood' disorders, such as:

- *Why is transition to adulthood a particularly problematic issue for those with genetic disorders and birth defects?*
- *How can transitions to adulthood of children with special health care needs be facilitated?*
- *What government-sponsored programs are available for care of children with special needs once they are no longer children?*
- *What are the roles of primary care providers, genetics care providers, and public health personnel in helping with the transition to adult care of those with genetic disorders or developmental disabilities?*
- *What special problems attend transitioning of care for those with genetic conditions, such as Turner syndrome, Marfan syndrome, and metabolic disorders?*
- *Why are data regarding health care needs of adults with many genetic conditions so limited and what can be done to address this?*

This brochure contains all the information you will need to know about attending the Transitions Conference, as well as an attached conference registration form. We must receive your registration form prior to October 21, 2005 in order to confirm your attendance at the conference. Attendance is limited 75 individuals. We will accept conference registrations on a first come, first serve basis.

TENTATIVE AGENDA

Friday, November 18th

- Registration** 11:00am – 12:00pm
Lunch 12:00pm – 1:00pm
Welcome and Introductions 1:00pm – 1:15pm
Plenary Session 1:15pm – 2:30pm
 General and Historical Overview of Transitions
Peter Scal, M.D., M.P.H.
Break/Hotel Check-In 2:30pm – 3:00pm
Plenary Session 3:00pm – 4:15pm
 Roles of Government, Public Health and Professional Organizations in Establishing Transitional Care
Eric Levey, M.D.
Plenary Session 4:15pm – 5:30pm
 Developing Model Transitions Programs
Robert Hopkin, M.D, Thomas Webb, M.D.
Dinner 5:30pm – 6:30pm
Patient/Parent Panel 6:30pm – 8:00pm

Saturday, November 19th

- Continental Breakfast** 8:30am – 9:30am
Special Transition Issues in Genetics
 Turner Syndrome 9:30am – 10:15am
Virginia Sybert, M.D.
 Marfan Syndrome 10:15am – 11:00am
Reed Pyeritz, M.D., PhD.
 Metabolic Disorders 11:00am – 11:45pm
Rani Singh, Ph.D.
Lunch 12:00pm – 1:00pm
Breakout Sessions 1:00pm – 2:30pm
 Medical Homes
Eric Levey, M.D.
 Developing Adult Natural Histories
Virginia Sybert, M.D., Reed Pyeritz, M.D., PhD.
 Case Studies in Transitional Care
Robert Hopkin, M.D, Thomas Webb, M.D.
Concluding Plenary Session 2:30pm – 3:00pm
 Making Health Care Transitions a Reality
Peter Scal, M.D., M.P.H.

**The final conference agenda will be sent to all confirmed conference participants in late October.*

SPEAKERS

Peter Scal, M.D., M.P.H. is an Assistant Professor in the Division of General Pediatrics and Adolescent Health at the University of Minnesota. He is also the Medical Director of the St. Joseph's Home for Children Community Clinic. Dr. Scal has written numerous articles concerning transitions to adulthood for children and adolescents with chronic conditions.

Thomas Webb, M.D. is a Pediatrician and Developmentalist at the Cincinnati Children's Hospital in the Division of Developmental Disabilities. He has a special interest in transitional needs for adolescents with developmental disabilities as well as health care delivery systems for individuals with developmental disabilities.

Robert Hopkin, M.D. is a Clinical Geneticist at the Cincinnati Children's Hospital who works with Dr. Webb at the adult genetics clinic. Dr. Hopkin also has a Neurofibromatosis clinic that involves transitional care.

Virginia P. Sybert, M.D. is a Clinical Geneticist at the University of Washington School of Medicine and is a recognized expert on Turner syndrome. She sees over 500 patients with Turner syndrome and has helped to delineate the natural history of the disorder.

Reed E Pyeritz, M.D., Ph.D. is Chief of the Division of Medical Genetics at the University of Pennsylvania School of Medicine. He has a special focus on genetic disorders of the cardiovascular system and has studied the cardiovascular complications of Marfan syndrome for over two decades.

Rani H. Singh, Ph.D. is the Director of the Nutrition Program at Emory University. She helps run a Metabolic Camp for young women, and her current research includes strategies for transitioning nutrition management in patients with metabolic disorders.

Eric Levey, M.D. is the Director at the Center for Spina Bifida and Related Conditions at the Kennedy Krieger Institute. He is also a Co-Chair of the Committee on Disabilities/CSHCN of the Maryland Chapter of AAP.

TRANSITIONS CONFERENCE REGISTRATION FORM

Name _____ Degrees _____

Title _____

Address _____

Email: _____ Phone: (____) _____

MEAL CHOICES

All meals are provided during this conference. Two meals require your selection beforehand:

Dinner on Friday, November 18th

Main Course

- Grilled Sirloin
- Raspberry Pecan Chicken
- Grilled Portabella Mushroom

Dessert

- Torte (please indicate chocolate, strawberry or black forest) _____
- Upside Down Cheesecake (please indicate topping: strawberry, raspberry, caramel or fudge sauce) _____

Lunch on Saturday, November 19th

- Deli Croissant (indicate ham, turkey, or roast beef) _____
- Oriental Stir Fry

Please note: Registrations must be received by October 21, 2005. Only 75 registrations will be accepted on a first come, first serve basis. A confirmation notice will be sent to each registrant.

Please detach registration page and mail to:

Attn: Conference Registration
c/o Lindsay Zetzsche • 335a Waisman Center
1500 Highland Avenue • Madison WI
53705-2280