



Coordinating Council for Children with Disabilities Symposium 2010

Caring for the Caregiver: Supporting Families in Caring for Children with Special Healthcare Needs and Disabilities

Friday, April 16, 2010
8:00am – 4:00pm
Alfred I. duPont Hospital for Children
Wilmington, Delaware

This conference addresses the challenges and barriers faced by family caregivers of children with special healthcare needs and disabilities and provides information on strategies that help overcome some of those challenges. Families will share their stories; panelists will address challenges and successes; and expert speakers will help participants gain knowledge and skills to overcome and address some of those challenges. This conference is geared toward families of children with special healthcare needs, healthcare providers, therapists, and community service professionals working with families and children with special healthcare needs and disabilities.

SCHEDULE OF EVENTS

- 8:00am - 9:00am: Registration & Continental Breakfast
- 9:00am - 9:15am: Welcome & Business Meeting
- 9:15am - 10:00am: Keynote Address: *Caring for the Caregiver*
- 10:00am - 11:00am: Panel Presentation
Parents as Caregivers: Experiences Shared and Lessons Learned
- 11:00am - 12:15pm: Workshop
Dynamics of Parent Engagement
- 12:15pm - 12:45pm: Lunch
- 12:45pm - 1:15pm: A Family Story
- 1:15pm - 2:15pm: Panel Presentation
Grandparent and Sibling Caregivers of Children with Special Healthcare Needs: Experiencing Unique Challenges
- 2:15pm - 3:15pm: Legal Considerations for Parental and Non-Parental Caregivers
- 3:15pm - 3:45pm: The Importance of HOPE: Connecting with Families of Children with Special Needs
- 3:45pm - 4:00pm: Evaluations & Wrap Up

Keynote Address: *Caring for the Caregiver*

Wilfried C. "W.C." Hoecke, M.Ed., *Director, Family to Family Health Information and Education Grant, Family Connection of South Carolina, Inc.*

Providing support and guidance for a family member with a disability can be complex and difficult. This keynote will address some of the important issues that caregivers face and provide suggestions for helping families cope with these issues.

W.C. Hoecke is currently the Director of the South Carolina Family to Family Health Information and Education Grant at Family Connection of South Carolina, Inc. He coordinates Family Connection's *Faith in Action Respite Project* and has worked for the past nine years helping to find respite solutions for South Carolina families. He volunteers as an associate chaplain at Lexington Medical Center where both his sons and his daughter were born and serves as a founding Board member of both the SC Respite Coalition and the SC Fatherhood Practitioners Network. W.C. Hoecke is a national trainer in fatherhood, respite, marriage, and faith-based initiatives, and he was the Practitioners Network 2005 recipient of the Joseph Osborne Fatherhood Trailblazer Award. He is the husband of Catherine and father of Karl (a 13-year-old with special needs), Franklin (11) and Anna (8).

Panel Presentation: *Parents as Caregivers: Experiences Shared and Lessons Learned*

Moderator: Tim Brooks, Ed.D., Advocacy Specialist, Center for Disabilities Studies

Panelists: Linda Hartzel; Suzanne Burnett; Karen and Jack Dettwyler

In most families, parents are the primary caregivers of children with special health care needs and disabilities. These parent panelists come from various backgrounds and family structures. They will review some of their experiences – difficult ones and joyful ones – and will discuss methods they used in dealing with parental stresses that allowed them to assist their children to grow and develop to their fullest potential.

Workshop: *Dynamics of Parent Engagement*

W.C. Hoecke, M.Ed., Family Connection of South Carolina, Inc.

In this workshop participants will explore the dynamics of remarkable, but sometimes fragile and often difficult, families of children with special needs. Participants will explore some of the family dynamics and what it is that causes these often-contentious encounters. Learners will discover practical ways to support parents, families and caregivers.

A Family Story

A remarkable local family, Jack, Cara, and Al Freedman, will share their family story with participants. Though the oldest son, Jack, has a disability, this extraordinary family has flourished. Participants will hear how they grew together as a family and how having a genuine connection with health care professionals helped them make it through the emotionally challenging times.

Panel Presentation: *Grandparent and Sibling Caregivers of Children with Special Healthcare Needs: Experiencing Unique Challenges*

Moderator: Bruce L. Orr, Parent, Family Voices of Delaware

Panelists: Carol Barnett; Tina Light; Francena Orr

Many times, other family members assist parents in caring for children with special healthcare needs or disabilities. However, in some instances, grandparents, siblings and others relatives become the primary caregiver for these children. This panel of grandparents and siblings providing care will present their unique challenges and talk about some of their positive and negative experiences as relative caregivers and what can be learned from them.

Presentation: *Legal Considerations for Parental and Non-Parental Caregivers*

Dan G. Atkins, Esq., Legal Advocacy Director, Delaware Community Legal Aid Society, Inc. (Disabilities Law Program)

In this presentation, attendees will learn about important legal issues that parental and non-parental caregivers of children with special healthcare needs and disabilities face, including guardianship, power of attorney, legal limitations of non-parental caregivers, etc. Attendees are encouraged to bring their own questions to this session.

Presentation: *The Importance of HOPE: Connecting with Families of Children with Special Needs*

Samtra Devard, Founder, HOPE Center Network for Families

Understanding the importance of HOPE in the lives of children with special healthcare needs and disabilities is the key to connecting with their families. HOPE can help ensure successful outcomes for these children and is the foundation for creating successful partnerships between professionals and families. This presentation will provide attendees with an understanding of the importance of focusing on children's possibilities and fostering strong partnerships between families and professionals.



CONFERENCE DETAILS

Registration: Pre-registration for the symposium is **strongly encouraged** but walk-in registration will be offered. Pre-registration is open until Monday, April 12, 2010. You can mail or fax your registration form to:

Medical Education Office
Alfred I. duPont Hospital for Children
1600 Rockland Road
Wilmington, DE 19803
Fax: 302.651. 6754

You can also register phone by calling 302.651.6751 or via email by emailing ccooper@nemours.org If you are paying by a credit card, please complete the registrations form found online at PedsEducation.org.

Cost: The cost for the conference is \$15.00 per person. Payment can be made via check (please make your check out to "Alfred I duPont Hospital for Children"). Payment can be mailed or dropped off at the registration table on the day of the conference. A limited number of stipends are available for parents and other family members who need this support to attend the conference. Please call 302.651.6751 for more information.

Schedule: The symposium begins with registration and a continental breakfast at 8:00am and concludes at 4:00pm.

Continuing Education Credits: Applications have been made to Delaware's Professional Boards of Regulation for Registered Nurses, Occupational Therapists, and Physical Therapists for continuing education credits. Each conference attendee will receive a certificate of attendance.

Questions?: Contact Dr. Louis Bartoshesky at 302.651.5916 or lbartosh@nemours.org; Samtra Devard at hopecenterofde@yahoo.com; or Ilka Riddle at 302.831.8186 or ikriddle@udel.edu

Directions: Call 302.651.6751 or go to <http://www.nemours.org/about/location/nchaidhc.html> The symposium will take place in the Lecture Hall on the 3rd floor behind the classrooms. Follow signs to the symposium.



REGISTRATION FORM

Please complete registration information and mail/fax, email, or drop off at the conference registration table.

Mailing Address:

Medical Education Office
Alfred I. duPont Hospital for Children
1600 Rockland Road
Wilmington, DE 19803
Phone: 302.651.6751
Fax: 302.651.6754

E-Mail Address:

ccooper@nemours.org

Your Name (one person per form): _____

Title (e.g. Parent, Nurse, OT, PT, etc.): _____

Affiliation (if any): _____

Street Address: _____

City, Zip, State: _____

This is a business or residential address (please check one)

Daytime Phone: _____

Email address: _____