

Taking Care of Our Children ...Taking Care of Ourselves

COME CELEBRATE OUR 25th ANNIVERSARY



Parents * Professionals * Children

Presented by:
The New England Regional Seminar for Families
of Children with Visual Impairments, Ages 0-7

May 3, 2008

8:15 a.m. to 3:00 p.m.

* * *

At:

Perkins School for the Blind
175 North Beacon Street, Watertown, MA 02472

General Information:

We encourage parents of young children (ages 0-7) with visual impairments or deafblindness and other family members and professionals throughout New England to come and participate in this opportunity to share our common concerns and to learn from one another.

Activities and childcare will be provided for your children by counselors assigned, according to your child's age, disability, and special considerations.

PLEASE CALL ELLEN MAZEL AT (781) 275-7875 OR E-MAIL AT MAZELS@VERIZON.NET AND LEAVE A MESSAGE IF YOU HAVE A LAST-MINUTE CHANGE OF PLANS REGARDING YOUR CHILD'S ATTENDANCE, OR IF YOU WOULD PREFER TO BRING YOUR OWN SITTER.

Parent Responsibilities:

- Bring a written schedule for your child's medications, meals, naps, and any other special instructions.
- Parents are responsible for administering all their child's medications and managing G-tube feedings.
- Label your child's clothes, toys, and/or special equipment.
- Bring any special equipment (stroller, porta-crib, highchair, wheelchair, etc.) and food or feeding equipment, which may help your child, feel more comfortable.
- Kitchen areas will be available for you to heat foods.
- Emergency number on the day of the conference is: **(617) 201-7512.**

For more information, please contact the following person(s) within your state:

MASSACHUSETTS	ANA QUINTANA NAPVI Office	(800) 562-6265 napvi@perkins.org
RHODE ISLAND	Linda Hughes RI State Services for the Blind	(401) 222-2300 Lindah@ors.state.ri.us
CONNECTICUT	Mary Lonergan BESB	(860) 602-4130 (800) 842-4510 Mary.Lonergan@ct.gov
NEW HAMPSHIRE	Beverly Temple MICE Program	(603) 228-1028 bevtemple@verizon.net
VERMONT	MELINDA Underwood VABVI	(800) 639-5861 X63 munderwood@vabvi.org
MAINE	Jean Small CC Maine	(207) 299-1933 jeansmall@ccmaine.org

Please call the contact person from your state if you are unable to pay the registration costs.

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AGENDA

7:30 - 8:00 All counselors check in at the Hilton Building Lobby. Head counselors meet with Tom and group contacts.

8:00 - 8:30 Counselors meet for orientation in the Auditorium

8:30 - 3:00 **EXHIBITS OPEN** - Hilton Building

8:15 - 9:00 **REGISTRATION AND COFFEE**

Parents bring children to counselors in assigned areas and have an opportunity to informally meet with other parents.

(PLEASE DO NOT BRING CHILDREN TO CHILDCARE BEFORE 8:30 A.M.)

9:10 - 9:25 **WELCOME ADDRESS - Update on National and Legislative Issues**

Hilton Building Auditorium, with:

Michael Bina, Superintendent of School Programs,
Perkins School for the Blind

Steven Rothstein, President, Perkins School for the Blind

Susan Laventure, Executive Director, National Association for Parents of
Children with Visual Impairments (NAPVI)

9:30 - 10:45 **MORNING CONCURRENT SESSIONS (Choose One)**

1. AMBLYOPIA, STRABISMUS & THE VISUALLY IMPAIRED CHILD

This session with Dr. Bacal will be a discussion of amblyopia, strabismus, refractive error and other aspects of visual impairment.

Presenter: Darron Bacal, MD, Ophthalmologist (CT)

2. BLINDNESS AND AUTISM

This session will look at how to discriminate the developmental aspects of blindness in deciding if a child with a visual impairment is on the autism spectrum.

Presenter: Elizabeth Field, Speech and Language Pathologist (ME)

3. LITERACY DECISIONS: THE ROLE OF THE LEARNING MEDIA ASSESSMENT

This session will describe the Learning Media Assessment and look at how it is mandated in the law as well as the role it plays in helping to determine your child's literacy media and the development of efficient skills in literacy.

Presenter: Tammy Reisman, Teacher of Students with Visual Impairments (MA)

4. INCORPORATING LITERACY FOR STUDENTS WITH MULTIPLE DISABILITIES AND/OR VISUAL IMPAIRMENTS

This session will offer an overview of literacy challenges faced by parents and teachers of students with multiple disabilities, ideas on how to incorporate literacy into everyday life, and ways to adapt books for all types of learners.

Presenters: Mary McAdams, Teacher of Students with Severe Disabilities/Deafblindness (MA)
Deirdre Leech, Teacher of Students with Severe Disabilities/Deafblindness (MA)

5. HOW TO BE AN EFFECTIVE MEMBER OF YOUR CHILD'S TEAM

This session will offer ideas on how to speak to the team from the perspective of your child so that team members understand. Justine will offer several ideas about how to be an effective advocate for your child in relation to service providers, administrators, educators, and peers.

Presenter: Justine Lyford, Parent (VT)

6. BUILDING SANITY INTO OUR LIVES-FOR OUR CHILDREN, FOR OUR MARRIAGE, FOR OURSELVES

This session will talk about what stress can do to relationships and personal health. The presenter will offer some strategies for coping, and answer questions. Rose tends to bring a lot of enthusiasm and humor to her sessions. Be prepared (or fore-warned)!

Presenter: Rose Marie Mallon, MS, MFT, MHC, Parent (MA)

**EXHIBITS WILL BE OPEN IN THE SECOND FLOOR LOUNGE
THROUGHOUT THE MORNING AND AFTERNOON SESSIONS**

10:45 - 11:30 SUPPORT GROUPS (Choose One)

1. Parent-to-Parent Support

These parent only sessions offer an opportunity for parents of children with similar visual and/or sensory impairments to meet and share their experiences and ideas. Please indicate on the attached registration form which group you plan to attend.

- | | | |
|--|---|---|
| <input type="checkbox"/> Aniridia | <input type="checkbox"/> Cortical Visual Impairment | <input type="checkbox"/> Coloboma |
| <input type="checkbox"/> Cataracts | <input type="checkbox"/> Glaucoma | <input type="checkbox"/> CHARGE |
| <input type="checkbox"/> Deafblind | <input type="checkbox"/> Multiple Handicaps/ | <input type="checkbox"/> Leber's Amaurosis |
| <input type="checkbox"/> Medically Fragile | <input type="checkbox"/> Mitochondrial Disorders | <input type="checkbox"/> Optic Nerve Atrophy/Hypoplasia |
| <input type="checkbox"/> Retinoblastoma | <input type="checkbox"/> ROP/RLF | <input type="checkbox"/> Other Visual Conditions |
| <input type="checkbox"/> Retinal Conditions | <input type="checkbox"/> Albinism | |
| <input type="checkbox"/> Anophthalmia/
Microphthalmia | | |

2. Grandparent-To-Grandparent Support Group

3. Professional-To-Professional Discussion Groups ~ These sessions are an opportunity for professionals to meet, ask questions and share their experiences and ideas on one of the related topics below. **(Choose One)**

- A. **AMBLYOPIA, STRABISMUS & THE VISUALLY IMPAIRED CHILD**, Darron Bacal, MD, Ophthalmologist (CT)
- B. **Blindness and Autism**, Elizabeth Field, Speech and Language Pathologist (ME)
- C. **LITERACY DECISIONS: THE ROLE OF THE LEARNING MEDIA ASSESSMENT**, Tammy Reisman, Teacher of Students with Visual Impairments (MA)

11:30 PARENTS PICK UP CHILDREN FROM CHILDCARE AREAS

11:45 - 12:30 LUNCH (TO BE PROVIDED)

12:45 - 2:00 AFTERNOON CONCURRENT SESSIONS (Choose One)

1. "WE CAN MAKE MUSIC!"

When life gets challenging, many of us naturally turn to music as therapy to 'de-stress'. Come learn what it is about music that helps us tolerate more difficult situations and how music therapy can be used to support learning objectives for our children.

Presenter: Jill Buchanan, Music Therapist (MA)

2. ADAPTING THE HOME & SCHOOL ENVIRONMENT FOR CHILDREN WITH CORTICAL VISUAL IMPAIRMENT

This session will highlight the behavioral characteristics of cortical visual impairment. The presenters will share ways to adapt environments and materials as well as share strategies to promote use of vision.

Presenters : Kimberly Conlon, Educational Consultant for Students with Deafblindness (NH)
Evelyn Kelso, Educational Consultant for Blind & Visually Impaired (NH)

3. AUGMENTATIVE COMMUNICATION FOR CHILDREN WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

This session will describe augmentative communication systems for children at varying developmental levels. It will also emphasize an approach to intervention which insures that current communication modes are not shortchanged while emerging modes are taught.

Presenter: Ellen Kravitz, Coordinator of Augmentative Communication Services, Easter Seals, (MA)

4. "ETIOLOGIES & SYNDROMES RELATED TO DEAFBLINDNESS" (INCLUDING CHARGE SYNDROME)

This session will overview information on syndromes that cause or include deafblindness. The presentation will include slides and discussion of various syndromes and information on some of their educational implications that may interfere with learning.

Presenters: Pamela J. Ryan, School Psychologist (MA)

5. WHAT DO WE MEAN BY SPECIALIZED SERVICES?

This session will discuss the why, what, who and how issues of providing specialized services to children with visual impairments or deafblindness.

Presenter: Tom Miller, Supervisor of Educational Partnerships (MA)

6. Parent Panel

This panel of parents will share their perspectives and invite discussion with participants regarding issues of parenting panel children with a variety of visual impairments, including blindness, cortical visual impairment, multiple disabilities, and deafblindness.

Panel: Janette Peracchio, Family Specialist New England Center DB Project (CT)
Scott Geraghty, Parent (NH)

Scott Lyford, Parent (VT)
Linda Hughes, Parent, (RI)

2:00 - 3:00 KEYNOTE ADDRESS:

PRESENTER: TOM SULLIVAN : Tom Sullivan, actor, singer, entertainer, author, and producer, graduated from Perkins in 1965. He served on the Student Council, was a star athlete, musician and singer. Tom was also a rebel who insisted he could do anything that a sighted person could do, which he documented in his 1975 autobiography, *If You Could See What I Hear*, later made into a major motion picture. He has authored numerous books. In *Adventures in Darkness* (2007), Tom hilariously recounts some of those more rebellious adventures at Perkins from which he took some serious life lessons. He has appeared frequently on *The Tonight Show*, performed in movies and television and was a special correspondent for ABC's *Good Morning America*. He is a much sought-after motivational speaker for corporations and universities.

3:00 PARENTS PICK UP CHILDREN FROM CHILDCARE AREAS

We gratefully acknowledge the following for providing support for this program:

Mr. Edward L. Bigelow, Jr.	MICE Program-NH
Mr. Geoffrey A. Brown, Jr.	Perkins Training Center
Dr. Andrew W. Chapman and Ms. Amy Schulz	The Edna L. Alizio Fund
Mr. and Mrs. George P. Denny, III	The Hilton/Perkins Program
Mr. and Mrs. William J. Edwards	CVS Foundation
Mr. William Gamelli and Ms. Tracy Vitols	Peabody Foundation
Ms. Elisabeth Gitter	
Mr. and Mrs. Robert W. Hagopian	
Ms. Sheila Kennedy	
Elaine and Timothy Mann	
Mr. Donald E. Marcus	
Mr. and Mrs. Charles C. J. Platt	
Mr. and Mrs. W. David Power	
Mr. Michael P. Quercio	
Ms. Amelie L. Ratliff	
John and Ellie Svenson	
Mr. Matthew B. Winthrop	
Mr. and Mrs. John Worrall	
Ms. Joan M. Youngman	

COMMITTEE MEMBERS

CT- Martha Delaney
Mary Lonergan
ME- Jean Small
MA- Ellen Mazel
Tom Miller
NAPVI- Susan LaVenture
Ana Quintana
NH- Beverly Temple
RI- Linda Hughes
VT- Melinda Underwood

Please be sure to complete all the information on the attached registration form and return it to us by April 11th.

If you are bringing your own childcare provider or have a last-minute change of plans regarding your child's attendance, please call **ELLEN MAZEL AT (781) 275-7875** or e-mail her at MAZELS@VERIZON.NET.
If you have any questions, please call your state contact or Tom Miller at phone: (617) 972-7331
Fax: (617) 972-7231, Perkins School for the Blind, Educational Partnerships office, or e-mail us at solair.kaya@Perkins.org.

If you need assistance in arranging overnight accommodations, please contact Linda Cummings at (617) 972-7393 or PreschoolServices@Perkins.org **no later than April 18, 2008**. A limited number of rooms are available on campus.

NEW ENGLAND REGIONAL SEMINAR

TAKING CARE OF OUR CHILDREN
TAKING CARE OF OURSELVES

Dear Parents:

Attached you will find a form asking whether or not you might want to become part of a Parent-to-Parent support network in your state. The purpose of this network is to enable service providers and the Commission or Parent Organization for the Blind in each state to connect parents of children with similar special needs for one-to-one information sharing. Parent organizations have found that such one-to-one contact and the ability to share information has proved very beneficial to both new parents and parents of older children.

Since we realize family conditions change over time, before your name would be given to another parent, you would be contacted about your desire to serve as a resource or just talk to another family at that time.

The parent members of our Planning Committee and statewide parent organizations hope that even if you cannot attend this conference, you would become part of this parent-to-parent support network. If you have any questions, please feel free to call one of the parent contacts in your state appearing on the brochure.

Thank you for your time and consideration.

Sincerely yours,

Tom Miller and The New England
Regional Seminar Planning Committee

P.S. Please return your response to:



Tom Miller
Educational Partnerships
Perkins School for the Blind
175 North Beacon St.
Watertown, MA 02472

PARENT-TO-PARENT SUPPORT

Family Name: _____

Address: _____

City: _____ State: _____ Zip Code: _____

Telephone (home): _____

Email: _____

Father's Name: _____

Mother's Name: _____

Child's Name: _____ Date of Birth: _____

Cause of Visual Impairment (if known): _____

<u>Blind</u>	<u>Visually Impaired</u>	<u>Deafblind</u>	<u>Physically Handicapped</u>	<u>Other Impairments</u>
_____	_____	_____	_____	_____
_____	_____	_____	_____	_____

Visual Condition: _____

Please note any other information that you feel may be important for Parent-to-Parent Support.

<u>Sibling's Name</u>	<u>Age</u>	<u>Any Comments</u>
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____

The goal of parent-to-parent support registration is to give any parent of a visually impaired child the opportunity to contact another parent whose child has similar concerns. You will be contacted prior to your name being given out to anyone.

I authorize the release of this information to the appropriate agency in my state and authorize my phone number to be given out to any parent of a visually impaired child.

Date: _____
Signature of Parent or Guardian

If you do not want to be contacted by another parent, please note. Under no circumstances will your name or number be released.

Perkins School for the Blind
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Watertown, MA 02472