

Batten Disease Support and Research Association



Conference 2010

**22nd Annual Batten Disease Support and Research Association
International Family Conference
“Field of Dreams and Hope”**

July 29-August 1, 2010
Chicago Marriott Oak Brook Hotel
Oak Brook, IL

Dear Parents and Family Members,

Included in this packet is everything you will need to know about the 2010 BDSRA Conference. Please know that many of the details are tentative. As we begin to finalize our plans, we will let our members know through our website (www.bdsra.org) and through our monthly News Flash e-newsletters.

This year's conference is co-hosted by the Midwest Chapter. These families, located in southern Wisconsin, western Indiana, and Illinois, have been working hard to make this a superb conference! We want to thank them for their hard work and dedication to BDSRA.

Hotel and Room Reservation Information

Chicago Marriott Oak Brook Hotel

1401 West 22nd Street

Oak Brook, IL 60523

Phone & Reservations: (630) 573-8555

Conference Name: Batten Disease Conference

Room Rate: **\$95.00/night** plus tax (currently 9%)

Website: <http://www.marriott.com/hotels/travel/chiob-chicago-marriott-oak-brook/>

Check-in time: 4:00 pm

Check-out time: 1:00 pm

The cut-off date to reserve your room and receive the special conference rate is **July 14, 2010 at 5:00 pm CST**.

There are 11 handicap accessible rooms available. To reserve a handicap accessible room, please contact BDSRA (1-800-448-4570) first to ensure you receive a room. BDSRA will make your reservation in your name for the room.

Hotel Amenities

All guest rooms come equipped with in-room coffee/tea maker, hair dryer, iron and ironing board, daily newspaper and an in-room safe. The hotel does provide high-speed internet in guest rooms for a fee of \$14.95 per day. Wi-fi internet access is provided free of charge in the hotel's public spaces, Business Center, and restaurants. The Oak Brook Marriott also has a large indoor pool and fitness center available to all guests. Room service is available from 6:00 am through 11:00 pm daily. The hotel provides a complimentary shuttle that will take hotel guests to destinations within 3 miles of the hotel.

Handicap parking will be available to those Conference attendees who need it. Parking spots will be clearly marked.

The entire hotel is NON-SMOKING. For those attendees who smoke, please use the receptacles/ashtrays located outside.

Hotel Restaurants

1401 West Restaurant and Bar offers a large selection of entrees for breakfast, lunch and dinner. Dress is casual.

Starbucks Café is open through the morning and mid-afternoon hours. Enjoy Starbucks' coffee, specialty beverages and pastries without leaving the hotel!

There are also many nearby restaurants available within walking distance and many located within the large shopping mall across the street from the hotel. The hotel provides a complimentary shuttle to anywhere within 3 miles of the hotel.

Airport Transportation

Transportation to and from both Midway and O'Hare airports is being provided by the Midwest Chapter. It is **VERY IMPORTANT** that you indicate your travel plans and details on the Conference Registration form. If your travel plans change, please alert BDSRA as soon as possible so that we may accommodate your new needs.

Conference Information

Registration Form

Located at the end of this packet is the official Conference Registration form. Please complete and return the form to BDSRA, no later, than July 23, 2010. There is no registration fee. You may return the form by either:

1. Email to donna@bdsra.org
2. US Mail: BDSRA, 166 Humphries Drive, Reynoldsburg, OH 43068

If you need to make changes to your Registration form, please call the BDSRA office at 1-800-448-4570 or submit changes to Donna at donna@bdsra.org.

Payment for meals and t-shirts can be made during Registration on Thursday or Friday.

Affected Childcare

Complimentary childcare will be provided for your affected child/ren of all ages, as well as siblings from age six months through five years. Parents are responsible for all meals and administering medication to their affected child. Please be sure to complete and return the Affected Childcare form at your earliest convenience. This form will be emailed to you if you have indicated on your Conference Registration form that you will be bringing your affected child/ren. Please review the agenda for times when childcare will be provided. You will be asked to provide your cell phone number to the care providers before leaving your child with them.

Research

We will have four groups conducting research this year with both the affected children and their family members.

University of Rochester

The University of Rochester Medical Center Batten Disease Diagnostic and Clinical Research Center will have a presence at the conference again this year. The neurologists and their team will be obtaining medical histories and performing neurologic examinations and assessments of children with Batten Disease. Appointments will begin Thursday afternoon. You may sign up for a time slot during Conference Registration on Thursday.

Massachusetts General Hospital

The group from MGH will be providing carrier and diagnostic testing blood draws. Individuals can also participate in the NCL Registry and Biorepository research independently or along with giving a clinical testing sample. If you are interested in having diagnostic or carrier testing done at the Conference, please notify BDSRA and we will email you the General Requisition Form required for testing. Payment for all diagnostic or carrier testing must be made at the Conference. The complete pricing list can be found on the BDSRA website. MGH does NOT bill insurance companies or patients. You must also make sure to list your referring physician's information. Sign-ups for this research will be available during Conference Registration on Thursday.

David Pearce, PhD and Chun-Hung Chan, PhD – Sanford Children's Research Center

A sample of blood (approximately 1-2 teaspoons), and/or cheek cells will be obtained from people with Batten disease, their parents and other family members at the annual Batten Disease Support and Research Association Conference (BDSRA) family conference. No other tests or procedures are involved. The procedures should take approximately 15 minutes to complete. Participants can include people who have been diagnosed with Batten disease, their parents, non-affected family members, and healthy volunteers. Sign-ups for this research will be available during Conference Registration on Thursday.

Dr. Christina Krause

This is a study consisting of reviewing the empirical literature concerning the effects of being an informal caregiver and the value of informal caregivers. It also examines the perceptions of health and control of health, intellectual achievements, self-identity, friendship and careers. The caregivers of children with Juvenile Battens (JB) Disease are part of a study which includes other caregivers who are caring for individuals of multiple, chronic conditions, and adults who are also informal caregivers. Very little is known about the needs of informal caregivers besides the meaningful work they do caring for loved ones. The goal of the study is to increase knowledge to the important role that these individuals perform. The testing is an assessment of instruments that include: the perceptions of control across many life domains, health locus of control and life satisfaction. This research is being conducted by Dr. Christina Krause, an Associate Professor at Aurora University.

This is a series of instruments that will take approximately twenty to thirty minutes to complete. The instruments will also be available in Spanish. The people we consider to be a caregiver could be any sibling who is 18 years or older, a neighbor, friend of the family, grandparents, cousins, aunt, uncle and anyone who routinely spends several hours a week helping a child with Batten. Sign-ups for this research will be available during Conference Registration on Thursday.

SIBS Program

The SIBS Program will be provided this year to siblings ages six and above. The SIBS schedule is included in this packet. The group will be going on three outings this year. All expenses and transportation are covered by BDSRA. If you indicate on your Registration form that an unaffected sibling will be attending the Conference, you will be emailed a Sibling Release form and a Sibling Code of Conduct form. Please complete and return these forms to BDSRA at your earliest convenience. Please note, participants of the SIBS Program will be provided lunch and dinner on Friday and lunch on Saturday. **DO NOT** include them in your meal totals on the Registration form.

First Time Conference Attendees

Families who are attending the Conference for the first time will receive a "Buddy Family". Your "Buddy Family" is an experienced Conference attendee and also has a child with the same form of Batten Disease that your child has. First time families will need to attend the New Family Orientation on Thursday evening at 6:30 pm to meet your "Buddy Family" and listen to an overview about the Conference.

If you are also a newly diagnosed family, there will be a special session for you on Friday afternoon at 3:00 pm. Please see the agenda for room location.

T-shirt Orders

T-shirts with this year's theme and logo are available for purchase. Affected children and siblings receive a complimentary t-shirt but still need to be included on the t-shirt order form included in this packet. T-shirts for adults and others may be ordered for \$4.00 each and will be available for pick-up during Registration. We **MUST** receive your t-shirt order, no later, than **July 10, 2010**. T-shirt order forms can be emailed to Donna at donna@bdsra.org or sent in with your Registration Form.

BDSRA Memorial and Memorial Service

If you would like to include your child's name on the **BDSRA Memorial**, please send the child's name, birth year and death year to Lance (bdsra1@bdsra.org) as soon as possible. We are accepting additions to the Memorial until **May 15, 2010**. If you submit a name after that date, we cannot guarantee that it will be on the Memorial this year, but we will do the best we can to add it.

If you would like your child's picture included in the **Memorial Service** slideshow, please email a picture to Amy Lombardi at kirka@bdsra.org. Please also include your child's full name, birth date and death date.

Conference Stipends

There is a limited amount of stipend funding available for families who need assistance to attend the annual BDSRA Conference. Stipends are:

- 1) Intended to assist families who have or had a child or children with Batten Disease by funding (1) room and/or meal expenses for the conference.
- 2) Restricted to immediate family members (mother, father, guardian/primary care provider, and siblings of affected child/children).
- 3) Provided based on available association funds with priority given to families who have or have had a child or children with Batten Disease who are attending the conference for the first time.

If you would like a Conference Stipend Request Form, please email bdsra1@bdsra.org or call the BDSRA National Office.

Oak Brook/Chicago Activities and Attractions

Oak Brook Center Mall
100 Oakbrook Center
Oak Brook, Illinois 60523-1808
Phone: 630-573-0700
www.oakbrookcenter.com
Located directly across from hotel

Graue Mill
3800 S. York Road
Oak Brook, Illinois 60523
Phone: 630-655-2090 or 630-920-9720
www.grauemill.org

Lincoln Park Zoo
2001 North Clark Street
Chicago, IL 60614
Phone: 312-742-2000
www.lpzoo.com
Open 365 days a year; always free admission

ESPN Zone
43 E. Ohio Street
Chicago, IL 60611
Phone: 312-644-3776
www.espnzone.com/chicago/
Sports dining and entertainment

Frank Lloyd Wright Home and Studio
951 Chicago Avenue
Oak Park, IL 60302
Phone: 708-848-1976
www.gowright.org
Admission \$15 for adult, \$12 children (4-17) and seniors (65+); admission includes guided tour

Magnificent Mile
North Michigan Ave
Chicago, IL
www.themagnificentmile.com
Over 1 mile of shopping and dining; explore over 460 exclusive stores and boutiques; enjoy fine dining at over 200 restaurants

Millennium Park
201 E. Randolph Street (Welcome Center)
Chicago, IL
Phone: 312-742-2963
www.millenniumpark.org
24.5-acre Park features the work of world-renowned architects, planners, artists and designers

Navy Pier
600 E Grand Ave
Chicago, IL 60611
Phone: 800-595-7437
www.navypier.com
Located on Lake Michigan; offers shopping, food, games, amusement rides and entertainment

Skydeck Chicago (inside Willis Tower)
233 S. Wacker Dr.
(Enter Skydeck on Jackson Blvd)
Chicago, IL 60606
Phone: 312-875-9447
www.theskydeck.com
Admission is \$15.95 for adults (ages 12+) and \$11.00 for children (ages 3-11)

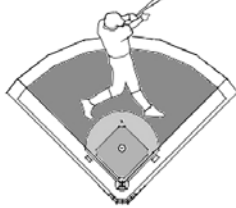
Shedd Aquarium
1200 S. Lake Shore Drive
Chicago, IL 60605
Phone: 312-939-2438
www.sheddaquarium.org
Admission is \$24.95 for adults (ages 12+) and \$17.95 for children (ages 3-11)

The Art Institute of Chicago
111 South Michigan Avenue
Chicago, Illinois 60603
Phone: 312-443-3600
www.artic.edu
Admission is \$18.00 for adults (ages 15+), students and seniors pay \$12.00; children 14 and under are free

The Hancock Observatory
875 N. Michigan Avenue
Chicago, IL 60611
Phone: 1-888-875-VIEW
www.hancockobservatory.com
Admission is \$15 for adults (ages 12+) and \$10 for children (ages 4-11)

Adler Planetarium and Astronomy Museum
1300 South Lake Shore Drive
Chicago, IL 60605
Phone: 312-922-STAR
www.adlerplanetarium.org
General admission is \$10 for adults and \$6.00 for children (ages 3-14)

BDSRA
CHICAGO 2010



Field of Hope and Dreams

Batten Disease Support and Research Association
22nd Annual International Family Conference
Oak Brook, Illinois
Thursday, July 29 - Sunday, August 1, 2010
Conference Agenda

<i>Wednesday, July 28, 2010</i>		
Time	Activity & Location	Attendees/Speaker/Notes
8:00 am - 3:00 pm	Golf Outing Willow Crest Golf Course \$40/golfer (includes cart fee)	Meet in the lobby at 7:00 am to carpool
<i>Thursday, July 29, 2010</i>		
Time	Activity & Location	Attendees/Speaker/Notes
10:00 am - 8:00 pm	Conference Registration <i>Salon G & H</i>	
12:00 pm - 4:30 pm	Optional Outing to Navy Pier <i>Meet in lobby at 11:45 am; busing provided; lunch and attractions on your own</i>	Please indicate on the Registration Form if you'd like to attend; first come, first serve basis
12:00 pm - 6:00 pm	Research Testing <i>Burr Ridge, Salon F</i>	MGH, University of Rochester, Dr. Pearce, and Dr. Krause
2:00 pm - 12:00 am	Hospitality Room Open <i>La Grange</i>	
6:30 pm - 7:30 pm	First Time Family Orientation <i>Salon C</i>	Tini Montavon Midwest Chapter
7:00 pm - 9:00 pm	Sibs Pizza and Pool Party <i>Hotel Pool</i>	
7:30 pm - 10:00 pm	Welcome Reception <i>Salon A</i>	Hosted by Midwest Chapter
9:00 pm - ???	Texas Hold 'Em Tournament <i>La Grange</i>	

Friday, July 30, 2010		
Time	Event and Location	Attendees/Speakers/Notes
7:00 am – 3:00 pm	Conference Headquarters Open <i>Salon H</i>	Conference Headquarters will be closed during lunch
7:30 am – 8:30 am	Breakfast <i>Salon A</i>	
8:00 am – Continuous	Batten Disease Memorial Open <i>Salon E</i>	
8:30 am – 12:00 pm	Affected Childcare <i>Elmhurst</i>	
9:00 am – 11:30 am	General Session <i>Salons B, C, D</i>	<ul style="list-style-type: none"> • Welcome by Midwest Chapter President Barb McDonough • BDSRA Today (<i>BDSRA President and Lance Johnston, Executive Director</i>) • Update on Research (<i>Sandra Hofmann, MD, PhD, Chair of Scientific Advisory Board</i>)
11:30 am – 4:30 pm	Life Goes On Outing* <i>The Morton Arboretum</i>	For those who have lost their child; Lunch will be provided
12:00 pm – 1:00 pm	Lunch Lunch with a Doc* <i>Salon A</i>	Sign up during Registration One representative per family please
1:00 pm – 5:00 pm	Affected Childcare <i>Elmhurst</i>	
1:30 pm – 3:00 pm	General Session: “Who will care for the caregivers?”* <i>Salon B, C, D</i>	Maria E. J. Kuhn, MS, NCC, LPC Christina Krause, PhD
2:00 pm – 12:00 am	Hospitality Room Open <i>La Grange</i>	
3:00 pm – 4:30 pm	Infantile and Late Infantile Women’s Group* <i>Salon D</i> Infantile and Late Infantile Men’s Group* <i>Salon G</i> Juvenile Women’s Group* <i>Marquis Room</i> Juvenile Men’s Group* <i>Salon C</i>	Lindsey Hurrle, MA Doug Cluxton, MA, LPC Maria E. J. Kuhn, MS, NCC, LPC TBD

* Indicates a session description is available on pages 13-16

Friday, July 30, 2010 cont.		
Time	Event and Location	Attendees/Speakers/Notes
3:00 pm - 4:30 pm	Newly Diagnosed Families <i>Salon B</i>	BDSRA Staff
3:00 pm - 4:30 pm	Grandparents' Group <i>Oak Brook</i>	Mike and Diane Carbrey
4:00 pm - 5:00 pm	Sib/Parent Panel* <i>Hinsdale</i>	
4:30 pm - 5:30 pm	Chapter Officers' Meeting <i>Westchester</i>	Chris Hawkins
4:30 pm - 5:30 pm	Special Needs Future Planning* <i>Wheaton</i>	Brian Rubin, J.D. Amy Lombardi, MSW, LSW
5:30 pm - 6:30 pm	Free Time	
6:30 pm - 7:30 pm	Dinner <i>Salon A</i>	
7:45 pm - 10:00 pm	Entertainment: Trivia Night <i>Salon A</i>	Hosted by Midwest Chapter
Saturday, July 31, 010		
Time	Event and Location	Attendees/Speakers/Notes
7:30 am - 8:30 am	Breakfast <i>Salon A</i>	
8:00 am - Continuous	Batten Disease Memorial Open <i>Salon E</i>	Being used by Sibs from 10:25 am to 11:30 am
8:30 am - 12:00 pm	Affected Childcare <i>Elmhurst</i>	
9:00 am - 4:00 pm	Healing Touch Room Open* <i>TBD</i>	Led by RoseAnn Liesen and Connie Vermeire Closed during lunch
9:00 am - 11:45 am (Break: 10:15 am - 10:25 am)	Track #1: Medical* <i>Salon C</i> Track #2: Batten Disease Education* <i>Salon D</i> Track #3a: Research* <i>Salon B</i>	Recognizing and Addressing Gastrointestinal Issues: TBD Understanding Genetics: Danielle Metterville, MS Behavior Management: Heather Adams, PhD Seven Deadly Sins: Common Mistakes That Lead to Litigation: Wendy Bills, PhD General NCL, INCL and LINCL Research: Jon Cooper, PhD, Sandra Hofmann, MD, PhD, Mark Sands, PhD, Colleen Stein, PhD, and Pascale Tiger, PhD JNCL Research: Colleen Stein, PhD, David Pearce, PhD, and Susan Cotman, PhD

Saturday, July 31, 2010 cont.

Time	Event and Location	Attendees/Speakers/Notes
9:00 am – 11:45 am <i>Break 10:15 am – 10:25 am</i>	Track #4: Grief and Bereavement* <i>Marquis Room</i>	A Portrait of Grief: Doug Cluxton, MA, LPC Finally, Grief: Vicki Scalzitti
10:00 am – 3:00 pm	Conference Headquarters Open <i>Salon H</i>	Conference Headquarters will be closed during lunch
12:00 pm – 1:00 pm	Lunch <i>Salon A</i>	
1:00 pm – 4:30 pm	Affected Childcare <i>Elmhurst</i>	
1:30 pm – 4:15 pm <i>(Break: 2:45 pm – 2:55 pm)</i>	Track #1 cont: Medical* <i>Salon C</i> Track #2 cont: Batten Disease Education* <i>Salon D</i> Track #3b: Fundraising* <i>Salon B</i> Track #4 cont: Grief and Bereavement* <i>Marquis Room</i>	Pain Management: Nancy Carney, RN Surgical Medical, Orthotic and Therapeutic Interventions for Pediatrics: Dr. Sue Mukherjee and Theresa Clancy Equipment Needs: Mike Collins, ATP, CRTS End of Life Issues: Doug Cluxton, MA, LPC Knock Your Fundraising Out of the Park: Adina Ryan Cure the “Field of Dreams” Syndrome: Adina Ryan Coping With Holidays and Special Days After a Loss: Karen Evans, MA Supporting Grieving Children: TBD
2:00 pm – 12:00 am	Hospitality Room Open <i>La Grange</i>	
4:30 pm – 6:00 pm	Free Time	
6:00 pm	Kids’ Parade “Take Me Out to the Ballgame” <i>Salon A, B, C, D</i>	Affected children and siblings <i>(meet in Marquis Room for preparation beginning at 5:30 pm)</i>
6:30 pm – 8:00 pm	BDSRA Award and Recognition Banquet <i>Salon A, B, C, D</i>	BDSRA President
8:00 pm – 11:00 pm	Entertainment & Sibs Dollar Dance <i>Salon A, B, C, D</i>	“Afterglow”, featuring the keyboard and vocal artistry of Gene Infelise, and the vocal stylings of Francesca

Sunday, August 1, 2010

Time	Event and Location	Attendees/Speakers/Notes
7:30 am – 8:30 am	Breakfast <i>Salon A</i>	
8:30 am – 12:00 pm	Affected Childcare <i>Elmhurst</i>	
9:00 am – 9:30 am	Christian Praise and Worship Service <i>Marquis Room</i>	RoseAnn Liesen Connie Vermeire
9:45 am – 11:15 am	Memorial Service <i>Marquis Room</i>	
11:15 am – 12:30 pm	Farewell Reception <i>Oak Brook Room</i>	

SIB Program Conference Agenda

Thursday, July 29, 2010

Time	Event and Location	Attendees/Speakers/Notes
12:00 pm – 8:00 pm	Conference Registration <i>Salon G & H</i>	Make sure you have turned in your Sib Release form and Code of Conduct form
6:30 pm – 7:30 pm	New Family Orientation <i>Salon C</i>	Brittany Carraciolo, Sib Leader
7:00 pm – 9:00 pm	Sibs Pizza and Pool Party <i>Hotel Pool</i>	
7:30 pm – 10:00 pm	Welcome Reception <i>Salon A</i>	Hosted by Midwest Chapter

Friday, July 30, 2010

Time	Event and Location	Attendees/Speakers/Notes
7:30 am – 8:30 am	Breakfast <i>Salon A</i>	
8:30 am – 9:00 am	Sibs Introduction <i>Salon A</i>	Brittany Carraciolo, Sib Leader
9:00 am – 11:30 am <i>(Break: 10:15 am – 10:25 am)</i>	Sibs 6-9 <i>Westchester</i> Sibs 10-13 <i>Wheaton</i> Sibs 14-17 <i>Hinsdale A</i> Sibs 18+ <i>Hinsdale B</i>	Lindsey Hurrle, MA, Art Therapist Marcie Smith, MS, LCPC Josh Bowen
12:00 pm – 12:30 pm	All Sibs load buses for Outing	Meet in hotel lobby
12:30 pm – 2:45 pm	Sibs Outing	Roller Skating USA Skate Center (lunch provided)
2:45 pm – 3:00 pm	Arrive from Outing	
3:30 pm – 5:00 pm	Swimming for Sibs 6-13 <i>Hotel Pool</i>	
4:00 pm – 5:00 pm	Sib/Parent Panel <i>Hinsdale</i>	
5:30 pm – 6:00 pm	Load buses for Outing	Meet in hotel lobby
6:00 pm – 9:00 pm	Sibs Outing	Amazing Chicago Funhouse Maze at Navy Pier (dinner provided)
9:00 pm – 9:30 pm	Arrive from Outing	

Saturday, July 31, 2010		
Time	Event and Location	Attendees/Speaker/Notes
7:30 am - 8:30 am	Breakfast <i>Salon A</i>	
9:00 am - 11:30 am <i>(Break: 10:15 am - 10:25 am)</i>	Sibs 6-9 <i>Westchester</i> Sibs 10-13 <i>Wheaton</i> Sibs 14-17 <i>Hinsdale A</i> Sibs 18+ <i>Hinsdale B</i>	Peggy Boehm Jennifer Otte, MA, LPC Dina Andriopoulos Josh Bowen
10:25 am - 11:30 am	Sibs Bereavement Session Ages 14+ <i>Salon E</i>	Doug Cluxton, MA, LPC <i>A session for sibs who have lost their sib(s) to Batten Disease</i>
12:00 pm - 12:30 pm	Load buses for outing	
12:30 pm - 4:00 pm	Sibs Outing	Lincoln Park Zoo (lunch provided)
4:00 pm - 4:30 pm	Return from outing	
5:00 pm - 6:00 pm	Free time	
6:00 pm	Kids' Parade <i>Salon A, B, C, D</i>	Affected children and siblings <i>(meet in Marquis Room for preparation beginning at 5:30 pm)</i>
6:30 pm - 8:00 pm	BDSRA Award and Recognition Banquet <i>Salon A, B, C, D</i>	BDSRA President
8:00 pm - 11:00 pm	Entertainment and Sibs Dollar Dance <i>Salon A, B, C, D</i>	"Afterglow", featuring the keyboard and vocal artistry of Gene Infelise, and the vocal stylings of Francesca
Sunday, August 1, 2010		
Time	Event and Location	Attendees/Speakers/Notes
7:30 am - 8:30 am	Breakfast <i>Salon A</i>	
9:00 am - 9:30 am	Christian Praise and Worship Service <i>Marquis Room</i>	RoseAnn Liesen Connie Vermeire
9:45 am - 11:15 am	Memorial Service <i>Marquis Room</i>	
11:15 am - 12:30 pm	Farewell Reception <i>Oak Brook Room</i>	

Session Descriptions (In Schedule Order)

Life Goes On Group Outing: The Life Goes On group will be going to the Morton Arboretum in Lisle, IL. The Arboretum has 1,700 acres of woods, gardens, lakes and prairie to explore and discover 365 days a year, rain or shine. Walking paths, roads, and trails lead you to collections and habitats that display the diversity of nature. Like in death, nature too will die. As in life we must renew ourselves and begin a new chapter in our lives, so too does nature, every spring or after a fire, nature renews itself. Come join us on Friday to renew life. We will gather in the lobby about 11:30 am and leave at 11:45 am. We will have lunch at the Arboretum and then take a one hour tour on a tram (which has room for two wheelchairs) through this natural beauty of landscapes that not only enhance our environment but will help make a greener, healthier and more beautiful world. We will return to the hotel around 4:30 pm. Please check out their website at: www.mortonarb.org.

Lunch With a Doc: This unique lunchtime opportunity gives parents a chance to sit, eat, and talk with the leading experts in Batten Disease. We ask that each family send only 1 representative per doctor/researcher. A sign-up form will be available starting Thursday during Registration. We will post a complete list of attending doctors/researchers on the BDSRA website as the information becomes available.

General Session: “Who will care for the caregivers?”: In the last 10 years what have we learned about caregivers? Even resilient individuals require personal strategies and ongoing support. We will explore various kinds of strategies that may help caregivers by supporting their resilience and reducing their stress. Ms. Kuhn and Dr. Krause have presented their research findings at many conferences across the country. They have also collaborated and co-authored a number of publications regarding caregivers and individuals who are dealing with multiple, chronic conditions.

Infantile and Late Infantile Women’s Group: This group is for mothers or female careproviders of children with Infantile or Late Infantile Batten Disease. Women in this group discuss a variety of topics including medical issues, caregiver stress, situations specific to their child and family, etc. A variety of subjects are covered across all stages of the disease.

Infantile and Late Infantile Men’s Group: This group is for fathers or male careproviders of children with Infantile or Late Infantile Batten Disease. Men in this group discuss a variety of topics including medical issues, caregiver stress, situations specific to their child and family, etc. A variety of subjects are covered across all stages of the disease.

Juvenile/Adult Women’s Group: This group is for mothers or female careproviders of children with Juvenile Batten Disease. Women in this group discuss a variety of topics including medical issues, caregiver stress, situations specific to their child and family, etc. A variety of subjects are covered across all stages of the disease.

Juvenile/Adult Men’s Group: This group is for fathers or male careproviders of children with Juvenile Batten Disease. Men in this group discuss a variety of topics including medical issues, caregiver stress, situations specific to their child and family, etc. A variety of subjects are covered across all stages of the disease.

Newly Diagnosed Families: This session is for families whose children have received a recent diagnosis (generally within the last two years) of any form of Batten Disease. We will discuss the basic genetics of the disease, talk about current and future research, and answer any questions attendees may have.

Grandparents' Group: This group is for the grandparents of children with all forms of Batten Disease. Grandparents hold a unique role in the lives of their children and grandchildren. Led by grandparents Mike and Diane Carbrey, this group discusses ways grandparents can support their children, fundraising ideas, and the affects of Batten Disease on extended family members.

Sibs/Parent Panel: This session gives parents the opportunity to talk with siblings about their experiences living with a child with Batten Disease. Parents are given the chance to ask questions. Siblings share stories, feelings, and experiences about their sibling with Batten Disease.

Special Needs Future Planning: Attorney Brian Rubin has dedicated his career to special needs planning for more than 28 of his 34 years in practice, because he, too, is a parent of a child with special needs. Brian's son, Mitchell, now 29, has Autism. Brian's presentation topics include government benefits, wills and trusts, adult guardianship and the alternatives, communication and navigating the "maze" of state services "when the bus stops coming". Discover professional advice...heartfelt compassion...and the unparalleled insight that only comes from living in a special needs family. This session is for any parent who has questions about their child's future when, by law, their child is no longer a "child".

Healing Touch Room: The Healing Touch Room is open to anyone interested in receiving individual prayer or spiritual comfort during the Conference. It is purely optional. The Healing Touch Room will be run by RoseAnn Liesen and Conni Vermeire.

Track #1: Medical

Recognizing and Addressing Gastrointestinal Issues: This session will cover gastrointestinal issues that children with Batten Disease may face over the course of the disease. Signs and symptoms of gastrointestinal problems will be discussed as well as treatment and remedies for these problems.

Understanding Genetics: A basic introduction to the genetics and inheritance patterns of the Neuronal Ceroid Lipofuscinoses. The session will also review enzyme and genetic testing and what these tests can and cannot tell us. Additionally, the speaker will explain the field of genetic counseling and describe a genetic counseling session.

Pain Management: You will review the definition of pain, the kinds of pain, what symptoms/causes trigger pain, barriers to effective pain management, goals and principles of pain management and a Batten Disease Pain Scale which was developed for BDSRA when our children become non-communicative in the disease process.

Surgical Medical, Orthotic and Therapeutic Interventions for Pediatrics: This session will describe various intervention available for children with developmental disabilities and explain how, when and why they are chosen. Interventions will include: hip and spinal surgeries, pharmaceutical interventions such as intrathecal baclofen infusion and botulinum toxin A; orthotic interventions for the lower extremities and spine and therapeutic interventions such as casting, taping and handling techniques.

Track #2: Batten Disease Education

Behavior Management: This session will review general principles of behavior management and provide suggestions for managing behaviors that are common in children with the various genetic forms of Batten Disease (primary focus on CLN3 disease/Juvenile-onset Batten). If time allows, the session will also briefly touch on education. An updated version of the handout for this talk will also be available, within 2 weeks after the BDSRA 2010 meeting, at:

<http://www.urmc.rochester.edu/neurology/Batten-disease-center/education.cfm>

“Seven Deadly Sins: Common Mistakes That Lead to Litigation”: Come and learn the “Seven Deadly Sins: Common Mistakes That Lead to Litigation.” This will be a fun, interactive session about IEPs. Please bring any questions you may have about your child’s IEP.

Equipment Needs: The presentation is a brief visual and hands on exposure to various types of durable medical equipment from walker to standers, strollers to wheelchairs.

End of Life Issues: This session will look at the challenges facing families and caregivers as they experience the inevitable decline that accompanies Batten Disease. We will explore palliative care needs and services as well as hospice. The difficult topics of managing quality of life and making end-of-life decisions will be explored.

Track #3: Research and Fundraising

General NCL, Infantile and Late Infantile Research: This session will include research presentations from scientists studying general NCL, Infantile and Late Infantile Batten Disease. Topics include:

- “What happens in the Batten brain? It’s all about communication...” presented by Jonathan Cooper, PhD
- “Combination Therapy for Infantile NCL” presented by Mark Sands, PhD
- "Toward enzyme replacement therapy of CLN1/PPT deficiency" presented by Sandra Hofmann, MD, PhD
- “Enzyme Replacement Therapy for CLN2” presented by Pascale Tiger, PhD, BioMarin Pharmaceuticals
- “Emerging therapies for CLN2 deficiencies” presented by Colleen Stein, PhD

Juvenile Research: This session will include research presentations from scientists studying Juvenile Batten Disease. Topics include:

- “Emerging therapies for CLN3 deficiencies” presented by Colleen Stein, PhD
- “Progress in JNCL research and how we are applying it to other NCLs” presented by David Pearce, PhD
- “Genetic guided approaches to NCL therapeutics” presented by Susan Cotman, PhD

Knock Your Fundraising Out of the Park: Learn the cardinal rules of planning fundraising events and creating brilliant fundraising letters. This session will focus on raising funds from individuals, planning and carrying out successful events, and do's and don'ts for successful appeals. CD's and handouts with information from this program will be available for all attendees.

Cure the “Field of Dreams” Syndrome: The myth "*build it and they will come*" doesn't always work, especially with online media. This session will focus on learning how to employ great strategies to capture attention, effectively get better event exposure, write news releases that will get published, market your events, and drive more traffic and donations to your websites. CD's and handouts with information from this program will be available for all attendees.

Track #4: Grief and Bereavement

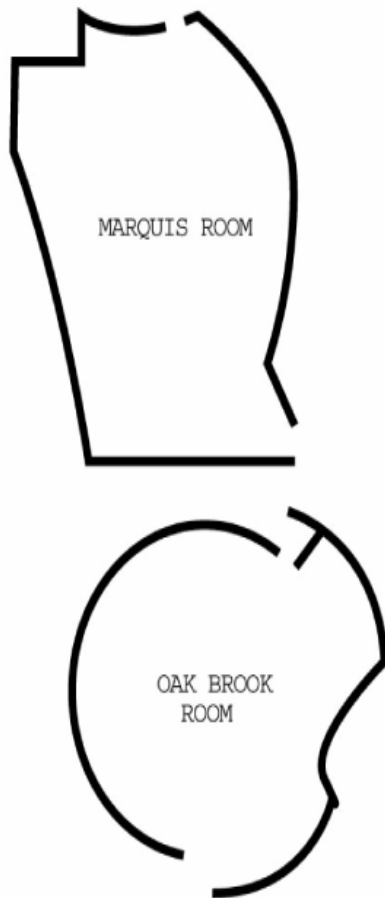
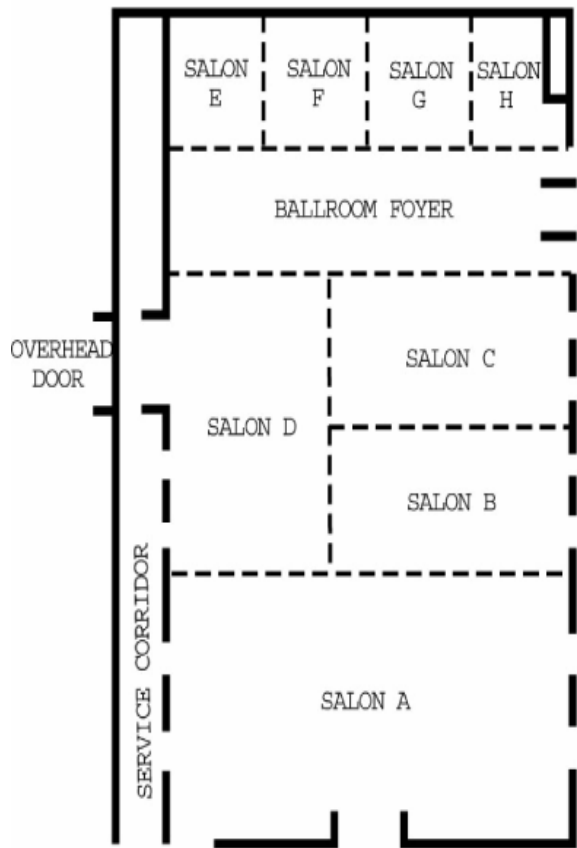
A Portrait of Grief: During this session, participants will examine grief as a normal response to change, loss and transition. We will discuss the tasks and work of mourning along with common reactions that people often experience. Practical ways to help the grieving person will also be explored.

Finally, Grief: For parents experiencing the joys and struggles of loving and caring for a medically-complicated child, grief is a constant companion – accompanying every loss and challenge that results from the progression of the disease. Immersing oneself fully in grief and experiencing its healing nature, however, is repeatedly put on hold as parents rally time and again to respond to the next loss in the disease process. This presentation will provide time to explore parental grief – in the time we care for our children, as we say goodbye to them, and as we mourn their loss.

Coping With Holidays and Special Days After a Loss: Holidays and special days can be especially difficult for those coming to terms with the absence of a loved one. These days intensify grief because they focus feelings of loss. Rituals help us acknowledge the loss and bring us comfort as we honor the one who has died. We will explore meaningful ways to remember and honor your loved one on these special days.

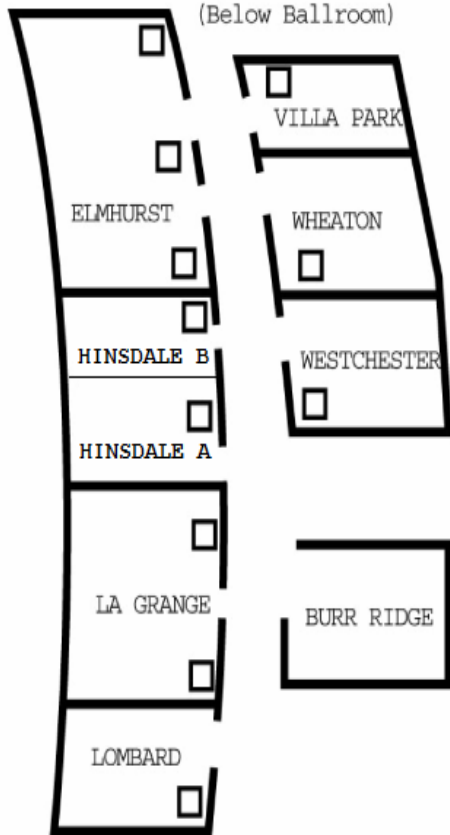
Supporting Grieving Children: TBD

MAIN LOBBY
LEVEL



OAK BROOK BALLROOM

LOWER LEVEL
(Below Ballroom)



Registration Form
2010 BDSRA International Family Conference
July 29th through August 1st, 2010
Chicago Marriott Oak Brook Hotel, Oak Brook, IL, USA

Last Name: _____

Address: _____ City: _____

State/Province: _____ Zip/Postal Code: _____

Country: _____ E-Mail Address: _____

Home Phone: _____ Cell: _____ Work: _____

What date will you be arriving in Chicago? _____

If you are flying into Chicago (Midway or O'Hare) we MUST know the following details:

Airport _____

Airline, flight #, date & time of arrival _____

Airline, flight #, date & time of departure _____

If you are flying into Chicago, will you need wheelchair transportation? Yes / No

Please circle form of Batten Disease/NCL: Infantile Late infantile

Variant late infantile (CLN 5 & 6) Juvenile Adult (KUFS) Other/Unknown

Please list only those that will be attending the conference that YOU PERSONALLY will be purchasing meals for. NOTE: Write the names as you want them to appear on the name tags.

Parents: (Dad) _____ (Mom) _____

- Number of conferences previously attended _____
- If you have attended previous conferences, would you consider being "Conference Buddy" for a new family at the reception on Thursday evening? YES / NO

Affected Children:

1. Name _____ Age _____ Kids Care Yes/ No

2. Name _____ Age _____ Kids Care Yes/ No

3. Name _____ Age _____ Kids Care Yes/ No

DOES YOUR AFFECTED CHILD REQUIRE OXYGEN? YES / NO

Angels:

Please provide the names of children no longer with you so they can be remembered at the Memorial service. Print name/s as you would wish them to be in the Memorial Program.

1. _____ 2. _____

3. _____ 4. _____

Siblings:

1. Name _____ Age _____ SIBS Program Yes/ No

2. Name _____ Age _____ SIBS Program Yes/ No

3. Name _____ Age _____ SIBS Program Yes/ No

4. Name _____ Age _____ SIBS Program Yes/ No

• Number of conferences previously attended? _____

• If none, would you like to be paired with a "SIB Buddy"? Yes/ No

Others: Again, please only fill in names for those, that you will be purchasing meals for. (Other relatives, Caregivers, Doctors, Scientists, Teachers, Etc.)

1. Name _____ Relationship _____

2. Name _____ Relationship _____

3. Name _____ Relationship _____

4. Name _____ Relationship _____

5. Name _____ Relationship _____

6. Name _____ Relationship _____

7. Name _____ Relationship _____

*If there is someone in your group who is purchasing their own meals, they MUST complete and return a separate Registration Form.

Optional Golf Outing

There will be a golf outing on Wednesday, July 28th.

If attending, how many will be playing? _____

Display Table

Will you need a display table for the conference? YES / NO

If yes, please list the purpose: _____

Optional Thursday Outing

There will be an optional outing offered on Thursday afternoon for those families interested in attending. A bus will be leaving at 12:00 pm to take 45 people to Navy Pier and will be returning by 5:00 pm. First come, first serve basis.

Please note: The bus is NOT wheelchair accessible.

YES, we will be attending. Total number of people going _____.

Memorial Service

If you will be participating in the Memorial Service, please send a photograph of your angel(s) with your registration form ONLY IF A PICTURE HAS NOT BEEN SENT IN AT PREVIOUS CONFERENCES. (Maximum photo size 4x6)

CUT OFF DATE MAY 30TH.

If you have any questions or concerns, please call BDSRA at 1-800-448-4570 or 740-927-4298 or e-mail bdsra1@bdsra.org

Please mail completed registration forms to: BDSRA 166 Humphries Drive, Reynoldsburg, OH 43068

This form will also be available on the BDSRA website. Download, complete and email to donna@bdsra.org

2010 BDSRA Conference

T-Shirt Orders thru BDSRA office only.

CUT OFF DATE FOR ORDERING: JULY 10th

(PLEASE, NO EXCEPTIONS)

Contact Information: donna@bdsra.org / 877-642-5512

T-shirts will be provided free of charge for affected children, children under age 4, and siblings. T-shirts for adults and others may be ordered at \$4.00 each.

T-shirt Sizes:

(Please note, the following are the only sizes available.)

Children "C" - Small, Medium, Large

Adult "A" - Small, Medium, Large, XL, XXL, XXXL

Sample A/XL

Affected Child Name: _____ Size: "C" or "A" _____

Affected Child Name: _____ Size: "C" or "A" _____

Affected Child Name: _____ Size: "C" or "A" _____

Affected Child Name: _____ Size: "C" or "A" _____

Sibling Name: _____ Size: "C" or "A" _____

Sibling Name: _____ Size: "C" or "A" _____

Sibling Name: _____ Size: "C" or "A" _____

Sibling Name: _____ Size: "C" or "A" _____

Parent Name: _____ Size: "C" or "A" _____

Parent Name: _____ Size: "C" or "A" _____

Other Name: _____ Size: "C" or "A" _____

Other Name: _____ Size: "C" or "A" _____

Other Name: _____ Size: "C" or "A" _____

Payment is due upon arrival and may be made via check, cash, or credit card.

