

THE MIRROR

The Newsletter of
IDEAS

IsoDicentric 15

Exchange, Advocacy & Support

SUMMER • 2007

Boston Conference Wrap-Up

By Jane True, editor

FROM OUR EDITOR
KOW ONB EDITOR

SHARING THE JOURNEY in Boston were 246 people representing about 98 families. We were thrilled to have 3 families from Canada and Europe was represented by 6 families! We did miss the Aussies this time. A highlight for everyone there was watching 45 of our beautiful children march in the opening parade carrying flags to create a display symbolic of the geographic diversity of IDEAS.



Conference feedback indicated that while most people found the sessions valuable, by far the favorite part of conference was meeting other families. In this issue of the Mirror you can read a new family's perspective on attending their first conference and get a sibling's reflections on what our conferences mean to her. Learn about how IDEAS is working with our European members to strengthen the support we offer to one another around the world.

A very important aspect of our conference is the convening of our researchers for the Research Roundtable before the conference even begins. This year we were quite pleased to have unprecedented attendance by quite a variety of professionals. Learn what took place at this session in several articles in this issue.

For those who were unable to attend, and for those who did, we have sprinkled conference photos throughout this issue taken by Will Sales and myself. Enjoy!

Jane serves as the editor of the Mirror. She raised Clare idic(15), and her two brothers, Toby and Tyler. She lives with her husband in Kansas City, MO.

Chromosome 15q duplication syndrome (dup15q) is a clinically identifiable syndrome which results from duplications of chromosome 15q11-13. These duplications most commonly occur in one of two forms. These include an extra isodicentric 15 chromosome, abbreviated idic(15), which results in an individual having 47 or more chromosomes instead of the typical 46. Individuals with an interstitial duplication 15 are born with the typical 46 chromosomes but have a segment of duplicated material within their 15th chromosome.

INSIDE THIS ISSUE

Conference Summary

- European Connection
- Research Roundtable
- Conference Pics
- New Family/New Perspective
- SUD Awareness
- In every issue:
 - Reflections from a Sibling
 - Reflections from the Listserve
 - Family Portrait
 - Cheers to our Volunteers
 - Birthdays

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Sharing Support and

Advocacy Around The Globe

by Jane True



ONE OF THE HIGHLIGHTS of the conference was the attendance by so many of our European families. A special session was held for the Europeans and a few of our IDEAS board members to determine how we can best work together to help our children. Attendees included families from Italy (2), Austria, Ireland, England, and the Netherlands. Dr. Agatino Battaglia, one of our professional advisory board members from Italy, and Donna Bennett, Nicole Cleary, Kadi Luchsinger, and Jim and Jane True were also present.

We determined that we have many areas of common interest such as identifying affected families, promoting research, and fundraising to support our needs. IDEAS needs help from European families with Parent Match and promoting the registry to support research. European families need help from IDEAS with obtaining



Back Row left to right: Agatino Battaglia (Italy), Camilla Patrizi (Italy), Alessandro Giuliani (Italy), Antal deWaij (Netherlands), Mr. Pail (Austria), Sarah Bowles (U.K.), Nick Bowles (U.K.)
Front Row: Natasja deWaij (Netherlands), Ursula Pail (Austria), Feldema O'Farrell (Ireland) Christine Reimann (Italy)

original materials and linkages to country-specific websites that are in development. Camilla is building a website in Italy and Antal is creating one for the Netherlands. We will coordinate our efforts. Additionally the Mirror will be made available for translation to those willing and able to translate. Initially Antal has offered to translate the Mirror into Dutch.

IDEAS and our collaborating researchers are investigating having a session on chromosome 15q duplication syndrome at the 2008 American Society for Human Genetics conference. Dr. Battaglia noted that many Europeans attend this meeting. IDEAS would like to be informed when the 2008 meeting of idic15-eu in Paris is scheduled. IDEAS would very much like to have a delegate at this meeting.

All present had a wonderful time together exploring ways in which we can spread our efforts of support and advocacy around the globe. Our meeting concluded with the group being led in Irish drinking songs by Ruth O'Farrell.



IDEAS CHEERS!

OUR VOLUNTEERS:

Mary and Joan
Ronan



CONGRATULATIONS to our Volunteers of the Quarter: Mary Ronan, grandmother to Jack Rasmussen, and Joan Ronan, Jack's aunt. Mary and Joan worked very hard for four days while attending the conference in Boston. Mary was a great help unloading and stuffing goody bags the first day. Both ladies worked the registration desk, handing out bags and directing people to the right places. They ran the IDEAS Store for two mornings. What started out as a 2-hour shift turned into the entire morning both Friday and Saturday, as they were selling so much and answering so many questions they couldn't close!

In addition, they assisted the Rasmussen family with childcare so Mom and Dad could attend sessions. Thank you Mary and Joan—IDEAS appreciates all your hard work!



Farewell to a Friend

Many of us have had the pleasure of spending time with Kevin Chamberlin and his family at the conference in Chicago and more recently in Boston. Even more of us got to know Kevin through his mother Nancy's participation on the listserv over the last nine years since they found IDEAS. Sadly, Kevin passed away in his sleep on Sunday, July 15. He was 11 years old. Goodbye, Kevin. We will miss you!



"There is always music
amongst the tree in the garden
but our hearts must be very quiet to hear it."

RESEARCH ROUNDTABLE

Nicole Cleary is the chair of the IDEAS board. In this role she coordinates research efforts for IDEAS. Nicole lives in Portland, OR with her husband Tim and three daughters.

One of the most rewarding parts of IDEAS conferences for me happens before registration even opens. Before every conference, IDEAS hosts a meeting of researchers interested in chromosome 15q duplication syndrome. Our 2007 meeting involved clinicians and scientists from all over the world. Interest in chromosome 15q duplication syndrome is growing, and our meeting reflected that!

Our meeting opened with a presentation by Dr. Carolyn Schanen, MD, PhD, from Nemours Biomedical Research. She provided a broad overview of the genotype and phenotype features of chromosome 15q11-13 duplication syndrome.

Dr. Edwin Cook, MD, from University of Illinois at Chicago, presented information about the current investigations into sudden unexplained deaths in dup15q syndrome. Meeting attendees discussed what will be important as this investigation moves forward.

Dr. Diane Chugani, PhD, from Wayne State University, shared the preliminary results from the children with chromosome 15q duplications who have participated in her study on imaging GABA-A Receptors with Positron Emission Tomography. She is considering seeking funding to move this study from a small pilot into a full research study.

Dr. Agatino Battaglia, MD, DPed, DNeurol, of the Stella Maris Clinical Research Institute in Pisa, Italy, shared several profiles of children he

has seen in his clinical experience with patients with chromosome 15q11-13 duplication syndrome. Dr. Battaglia has extraordinarily detailed data on the children involved in his clinic, and it was helpful for the attendees to consider in light of the pressing discussion on sudden death.

The meeting wrapped up with a discussion of new research directions. Carolyn Schanen provided a summary of the new research study being conducted by Dr. Lawrence T. Reiter, at the University of Tennessee Health Science Center. He is conducting a study of Phenotypic analysis of interstitial duplication 15q11-q13 patients. Dr. Michael Cuccaro, Miami Institute for Human Genomics, provided a comprehensive overview of the developing International Chromosome 15q Duplication Syndrome Registry. The

registry is designed to meet the needs of both families and researchers for comprehensive clinical information about dup15q syndrome. With this registry we will finally be able to fully characterize chromosome 15q duplication syndrome and establish the natural history of this disorder that affects all our families.

In addition to the presenters already mentioned, IDEAS would like to thank the clinicians and scientists who attended the meeting and contributed important information and insights to our discussion. Brenda Finucane, MS, CGC, Elwyn Training & Research Institute; Margaret Bauman, PhD, Harvard University & LADDERS; Alycia Halliday, PhD, Autism Speaks; Jane Pickett, PhD, Autism Tissue Program; Carolyn Komich Hare, Autism Tissue Program; Janine LaSalle, PhD, UC Davis; Sarah Spence, MD, PhD, National Institute of Mental Health; Jane Yip, PhD, Boston University School of Medicine; members of the IDEAS board and research committee. Thanks everyone!



Front Row left to right: Sandy Thevarkunnel, Margaret Bauman, Janine LaSalle, Sarah Spence, Mike Cuccaro, Agatino Battaglia, Carolyn Schanen;
Back Row: Alycia Halliday, Jane Yip, Carolyn Komich Hare, Jane Pickett, Ed Cook, Brenda Finucane, Diane Chugani



Sharing the Journey
15
www.idic15.org

Conference 2007

Sharing the Journey...Baby Steps

We are the Peters Family, Jack (Dad), Gina (Mom), Sam (6 years), Madeline (4 years) and John Paul (JP) idic15 (14 months).

Our journey began very joyfully on May 11, 2006, when JP was born. As he approached four months we saw the first red flags. He was very floppy, he wasn't tracking well with his eyes and he didn't move his head to the left. On December 5, 2006, our journey took a turn we never could have imagined. JP had



an EEG that day and we were told that the EEG pattern was called hipsarrythmia. The doctor told us that JP was experiencing the onset of Infantile Spasms. Despite ACTH injections and other seizure medications, JP's seizures proved to be difficult to manage. During a second hospital stay in December we were informed that one of the labs done on JP had come back abnormal and showed a duplication on chromosome 15. The doctors could not provide us with information about duplications on chromosome 15, so Jack began to look for information on the internet about isodicentric 15 and that was our first introduction to IDEAS. The more we read, the more we knew that the IDEAS website explained what was happening to JP.

Initially I was too overwhelmed and scared to reach out to anyone. But as JP's seizures became worse and the side effects of the medication stole away our precious baby I desperately needed to find someone who could help us understand what was happening. I first spoke to Kadi Luchsinger and within days she connected me with Dr. Carolyn Schanen and several moms with similar experiences. Words cannot express the gratitude I have for these amazing women. They opened their hearts to me and revisited a place that I am sure they would rather forget, in order to give me comfort. They were my life-line in the weeks and months that followed.

It quickly became apparent that we knew more about idic15 from the IDEAS web site and the IDEAS parents we had spoken to than any of our local doctors. We began printing out pages from the IDEAS

web site and giving them to JP's doctors and therapists at all of his appointments. We knew that the best way to help JP was to educate ourselves and when we learned about the conference we decided it would be a priority for us to attend.

On June 27th, as we were checking into the Seaport Hotel, Donna Bennett, whom we had never met before, approached us and asked if we were there for the IDEAS conference. Her warm welcome immediately confirmed for us that we were exactly where we needed to be. We had been looking forward to meeting the families and the women who had provided us so much support, and finally meeting them and thanking them in person was one of the best parts of the conference. It was fun and encouraging to watch the opening parade with all of the children in attendance. We were extremely impressed by the caliber of doctors, therapists and other professionals who presented each of the sessions and by the scope of topics that were covered. A particular highlight of the conference was when Rick Guidotti photographed JP and told me he thought JP was such a beautiful and amazing baby. After months of hearing all kinds of frightening medical terms used to describe JP's condition, it was very healing when Rick described JP with words that every mother wants to hear.

Jack and I left the conference feeling inspired by so many courageous, motivated and informed families, willing to share their joys and heart breaks, believing in their children, desiring more for them, loving them unconditionally, and sacrificing so much. Our journey started only a few months ago and we felt like we were stumbling more than walking. Now that we have attended the conference we are so grateful to be sharing the journey, knowing that there is a hand to reach out to when we lose our balance and offering a hand to others when they need help too.

HAPPY BIRTHDAY
TO YOU!



Erika M	7/1/01	Charlotte J	8/28/03
Kyle B	7/1/84	Rachel H	8/29/03
Travis R	7/2/98	Ashley Q	8/29/91
Alexis M	7/5/94	Shannon N	8/30/94
Samuel V	7/9/95	Kacey T	8/30/93
Michael B	7/9/84	Joshua D 	9/1/94
Lauren C	7/11/00	Brenda M	9/2/89
Andrew H	7/11/89	Claire G	9/7/82
Gabrielle P	7/12/01	Cheyenne D	9/8/92
Erica A	7/12/86	Bente S	9/9/97
Christine D	7/13/91	Elana K	9/9/88
Jessica M	7/18/98	Dante R	9/10/98
Nicolas D	7/18/95	Major R	9/10/98
Ashtyn M	7/23/04	Thomas N	9/10/93
Clare T 	7/25/80	James S	9/11/93
Zoe N	7/25/02	Waawijja W	9/11/93
Colin O	7/30/98	Casey W	9/12/03
Emily M	7/31/80	Julia W	9/12/96
Rachel K	8/4/86	Raquel A	9/14/00
Devon J	8/7/93	Rachel M	9/14/94
Jesse M	8/12/94	Breauna E 	9/15/95
Eli C	8/14/92	Mason L	9/15/99
Austin V	8/15/96	Cameron P	9/17/00
Spencer G	8/15/94	Jeremy L	9/17/88
Patrick S	8/16/98	Conor M	9/19/96
Carly P	8/16/93	Sarah L	9/23/95
Gavin H	8/17/04	Brandon J	9/24/97
Alicia M	8/19/97	Miranda H	9/25/94
Sarah D	8/23/98	Evan M	9/28/94
Colt C	8/24/93	Stephen G	9/30/99
Marian I	8/25/92	Cara Vandeven	9/30/92



Welcome to New Families

IDEAS welcomes the 21 families who have joined us in the last quarter, including one family who found us after the death of their daughter Alice. Alice was 13 years old, and we are told she was much loved by all who met her. There was a friendliness about her which could not be ignored. Our thoughts and prayers are with Alice's family.

KEEP IN TOUCH...



Please send your
change of address
to
info@idic15.org

Facing the Fear of Sudden Death in Dup15q

IN THE 15 MONTH PERIOD between April 2006 and July 2007 IDEAS learned of the sudden and unexpected deaths of five seemingly healthy young people with chromosome 15q duplication syndrome. In this same time period, another three medically fragile children with duplications of chromosome 15q11-13 passed away. Given this significant cluster, the IDEAS professional advisory board immediately began work to investigate why this is happening, what parents can do, and what research can offer. IDEAS advisors have created a physician alert describing this situation that families can share with your child's doctors. A copy of the advisory can be found as a special pull out in this issue of the MIRROR and is also accessible from the IDEAS website (www.idic15.org). The goal of this article is to provide additional information about the current state of our investigation.

WHAT WE KNOW The five cases of sudden and unexpected death involved young people between the ages of 10 – 26. Four were young women and one was a young man. All five died during the night while they were in bed, presumably asleep. Parents reported hearing nothing alarming during the night. These young people were described by their parents, therapists and doctors as lively, energetic, and affected by the cognitive disability, autism and ADHD that are frequently experienced by individuals affected by dup15q syndrome. One had an interstitial 15q11-q13 duplication, and the others had isodicentric duplications. Four of the five young people had identified seizure disorders. One had no identified seizures but had recently had two nocturnal episodes which could have been seizures. Among the four young people with confirmed seizures, one had no recent seizures, and the other

three had seizures that were described as well-controlled at the time of death. The three medically fragile children had all experienced significant deterioration as their neurological status became more involved. They were between the ages of 10 – 12 when they passed away.

WHAT WE ARE LEARNING Four of the families made a brain tissue donation at the time of their child's death. The Autism Tissue Program (ATP) is coordinating the neuropathological exams. The first two donations have been imaged and the processing has started. The ATP is using newest protocol to provide any possible cause of death via neuropathology exam as well as vital research information. The ATP will generate a report for the parents, and additional documents for the medical examiners and IDEAS professional advisors in the fall of 2007.

There were two autopsies performed. The first autopsy report stated that no satisfactory anatomical explanation of the death was found. The second autopsy report has not yet been released. Comprehensive autopsies after a sudden death are critical in our search to determine what is happening to these young people.

WHAT FAMILIES CAN DO Parents raising children with chromosome 15q duplication syndrome are understandably alarmed at learning of these sudden deaths. *While the investigation continues, parents are encouraged to educate their child's doctors.* Bring them a copy of the physician advisory included as an insert in this issue or go to: http://www.idic15.org/dr_suddendeadth.php to reprint. You will be bringing them new information since there are not yet any published case reports. You and your

child's doctors should discuss your child's medical history, and the pros and cons of additional evaluation.

IDEAS is asking families to share any findings discovered through additional medical testing. Reports of both normal and abnormal findings will be helpful. IDEAS professional advisors will be informed about unusual cardiac or respiratory findings (especially during the night). Families are encouraged to contact

Nicole Cleary, M.S.S.
IDEAS Board Chair
503-253-2872
nicleary503@comcast.net

ADVANCE PLANNING Families are strongly encouraged to consider if they would be willing to request an autopsy and/or make a brain tissue donation at the time of their child's death, whether it is sudden and unexpected or at the end of a more normal life span. Comprehensive autopsies and brain tissue are absolutely critical for ongoing research efforts. General autopsy may not provide the information necessary to understand the cause of death. It has been our experience that the families have to advocate strongly for a comprehensive autopsy (one that focuses especially on heart and lungs). Unfortunately there can be resistance to performing a comprehensive autopsy because of the known chromosomal abnormality. IDEAS is developing a support team that can assist parents at the moment of their child's death and IDEAS will cover the costs associated with comprehensive autopsies. The Autism Tissue Program is the resource for families wishing to make tissue donations. Families can pre-register with the ATP on their website, www.memoriesofhope.org.

If your family wishes to have a comprehensive autopsy and tissue donation at the time of your child's

death, you are encouraged to discuss your wishes with extended family, friends and physicians who can support you at this difficult moment. IDEAS is developing a document that families can use to express their wishes. Please watch for updates in the MIRROR.

In Summary

While we do not have definitive answers, we can state that there is probably an increased risk of sudden, unexpected and currently unexplained death in chromosome 15q duplication syndrome. Parents should discuss this new risk with their child's physician so that they can be alert for potentially relevant symptoms. IDEAS has been critical to identifying this problem and has engaged scientists and clinicians from around the world to understand the problem. Working together, we will continue to learn more. Our emphasis today needs to be on loving and caring for our children, and appreciating the special time that we have together each day.

*Contributing authors include IDEAS Professional Advisors: **Agatino Battaglia, M.D., DPed, DNeuro**, Stella Maris Clinical Research Institute; **Edwin H. Cook, M.D.**, University of Illinois at Chicago; and **Carolyn Schanen, M.D., Ph.D.**, Nemours Biomedical Institute. Additional input provided by **Vicki Miller, P.A.**, Brown University Program in Medicine; and **Nicole Cleary, M.S.S.**, IDEAS Board Chair.*

YOU ASKED FOR IT...



YOU GOT IT!

The IDEAS Store is pleased to announce we have expanded
Just in time for Holiday shopping!

To make room for these new items,
we are marking down other merchandise!

NEW:

Men's Ping Pullover short-sleeved golf jackets!

Women's fleece jackets!

Hoodies for adults and youth!

#15 awareness pins in pewter!

Note cards featuring our kids' artwork!

2008 Calendars featuring Rick Guidotti's pictures of our children!

CHECK THESE ITEMS OUT AND MORE AT THE
IDEAS STORE at www.idic15.org!

IDEAS now accepts Visa and MC, call Lori at 781-575-0847 for
orders or download the order form on the website.



Please Help Support IDEAS

IDEAS is a completely volunteer run non-profit organization dedicated to providing family support, raising awareness, and fostering research into chromosome 15q duplication syndrome. IDEAS relies on the involvement of families to help us raise money to accomplish our mission.

Reflections
 Reflections

This part of the REFLECTIONS column shares perspectives from a sibling.

Reflections from a Sibling

by Shelbie Johnson 12, sister of Alexis 5, idic(15)

MY NAME IS SHELBBIE AND I'M 12 YEARS OLD.

I have two sisters, one who's 16 and another who's 5. Alexis is my younger sister who has idic15. Our family has attended the last three idic15 conferences. We were lucky with the first one because it was only an hour away from home in Philadelphia. For the second conference in Chicago we added a week for a family vacation to Cedar Point. During our third conference in Boston my Aunt and Papa flew in to help us and tour Boston. We try to tour each city for a couple of days either before or after the conferences and plan our family vacation around them. I've enjoyed attending each time while seeing and meeting all the children with idic15. I always try to imagine how my sister Alexis will be at different ages. I've noticed that some of the children talk and some don't.

I hope that they all will learn to talk. For my little sister, I pray that she will talk one day. Without her talking, my family can't tell if she is hurt or sick sometimes. In Chicago and Boston, the sibling classes I went to were very good. Even though I didn't talk much, I could hear some of the things other brothers and sisters were going through with their siblings who have idic15. There was this lady there that had all these great ideas that I could do with Alexis. There was one girl there, a sister who talked and shared a lot, it was nice listening. She told us all these different stories about her brother. In my mind I wondered if my sister would be like that or if she would do any of the things that her brother did. I met Hannah, a good friend of mine, four years ago during the Philadelphia conference. We became closer in Chicago and then I felt very close to her in Boston. Her family is always nice and talks to me and my family. It's nice that she is only a year younger than me so I can talk to her and tell her anything that is on my mind. My mother loves to be around her mother, she says that she's fun. I like seeing the same friends every two years. We catch right up and laugh and swim during the days and nights. Chicago's hotel had the nicest pool yet. One of the nicest people at the last two conferences is the photographer Rick; he loves to take pictures of all of the children. I enjoyed going to the Chicago zoo for the idic15 conference family outing. I hung out with Hannah all day. I loved going to the Boston Children's Museum for the idic15 conference family outing. I wonder where we'll go during the Indiana conference.

After listening to my mom talk to other parents about their kids, I have learned how hard our idic15 children can become over the years. One family that we know has a little son Nicholas who has idic15 and he is adorable. I absolutely love little kids so I kept picking him up and talking to him during the Boston conference. When I look back into the past I realize that Alexis was the same as him when she was younger. I can imagine her being a lot like the older kids when she grows up.

I will love to go to the next conference. I will be able to see how all of the kids have changed, improved with speech and how they are moving around. I hope that other people will be expecting the same thing when they go to the next conference. When I see kids get better or learn something new it's like a miracle. My little sister does that all of the time. When she learns something new she expects us to clap for her and give her a piece of candy. I would like to know if any of the other parents give stuff or treats to their kids.

I want to work with special needs children when I get older so going to the conferences helps me learn. I hope that the next conference will be fun and another good experience for me and my family.



Reflections Reflections

We are looking for siblings who would like to share their thoughts in a future issue of the Mirror. If you are interested, please contact the editor at jtruo@kc.rr.com

Did you know?

Duplications of chromosome 15q11-q13 are the most frequently identified chromosome problem in individuals with autism.

This column is designed to share
perspectives from recent
Listserve discussions.

Reflections Reflections

Reflections From The Listserve ONLINE CONFERENCE

"Sharing the Journey", the 2007 Conference theme, was experienced worldwide in an impromptu Listserve Mini Conference. Many who were unable to be in Boston connected online to share laughter, tears and inspiration. Topics ranged from weather to the isolation of having a special needs child. People at the Boston conference joined in with encouragement and reports on the conference. At the end of the three days, door prizes were awarded. Thanks to all who participated, and especially to Alison Kalnicki for coming up with this great idea!

Fundraising Successes

BY FRANK KOBUSEWSKI, FUNDRAISING CHAIR



NOW IS A GREAT TIME FOR A FUNDRAISER!

After some fantastic teamwork raising money at our conference, I would like to let you know we still need help closing our budget gap. No matter how small a donation, each one gets us closer to our goal of helping provide a better tomorrow for children with chromosome 15q duplication syndrome.

There are many options for fundraisers, such as: backyard barbecues, jewelry or candle parties, small raffles, dinner/night on the town.

A friend of ours, Jodi Miller, recently had a very successful fundraiser by organizing a night at a local restaurant. IDEAS got a percentage of sales all day long on the chosen day from anyone who dined there and presented the IDEAS flyer. Jodi also organized a raffle and silent auction that evening.

Doreen Gladys reports that during the month of May fifteen families participated in IDEAS First Annual Phantom Tea. They each sent out a minimum of five invitations to five friends, acquaintances, and family members. Many of the invited responded by sending a donation to IDEAS. These fifteen families generated approximately \$4500 in donations. Watch for the Second Annual Phantom Tea in May 2008.

Thanks to all who have helped in this crucial area this year.

More Successes: The 2007 conference raffle and silent auction raised \$4285!

IDEAS

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IDEAS is a non profit organization that provides family support and promotes awareness, research and targeted treatments for chromosome 15q duplication syndrome. IDEAS offers help and hope for chromosome 15q duplications.



SAVE THE DATE...
2009 IDEAS Conference

June 25 - 27, 2009 • Crowne Plaza Hotel • Indianapolis, Indiana

Mid-Atlantic Regional Gathering:
August 25th, 2007

Meet at the home of Cynthia and Andrew Johnson in Wrightstown, New Jersey at 1 p.m. on Saturday, August 25th for an afternoon of BBQ and swimming. For more information, contact Cindy Johnson at cynthiaj100@verizon.net or 609-723-7731.

Northwest Regional Gathering:
September 1, 2007

Come join the Northwest IDEAS families at Maryhill State Park at 11 a.m. on Saturday, September 1st. We meet on the bank of the Columbia River and share picnic lunch and a fun afternoon together. For more information, contact Nicole Cleary at 503-253-2872.