

The ALPHA Report

American Lead Poisoning Help Association

Summer 2007

Volume 3, Issue 2

Where are the Parents?

June was a great month for ALPHA parents to vent frustrations! ALPHA expanded coverage, venturing into MySpace June 2007 to reach even more parents. Brenda Music, Founder of Iowa Parents Against Lead, is the group moderator. Brenda posed the following question: "Why do we feel so alone when we hear our child was poisoned? The national average is what...1 out of 11 kids lead poisoned? In Iowa it's 1 out of 7 kids. So with all these children poisoned ~ that I assume all of which have parents ~ why did I feel so alone and why do others?"

In other words, WHERE ARE THE PARENTS? Parents need to understand that lead prevention begins with them. Parents deal with the long-term effects of lead 24/7 in raising children who have histories of lead exposures, and that can be overwhelming. ALPHA is trying to locate these families, to let them know that they are not alone anymore.

There are parents who believe lead poisoning is a stereotype, that lead is something they can ignore after a positive lead screen. These parents hope lead just goes away so they aren't embarrassed about what others think. Lead doesn't go away, and the embarrassment is nothing compared to the behavioral problems when that child becomes a teenager. **There is no safe level of lead in the human body; the effects of lead are permanent.**

Due to HIPA restrictions, the only way ALPHA can reach out to families affected is to have health departments include information on how to contact ALPHA for support. Include a copy of this newsletter in your mailings, as an example. Parents are encouraged to sign-up for on-line groups, including:
<http://health.groups.yahoo.com/group/ALPHALEAD>
<http://groups.myspace.com/ALPHALEAD>

For more information about the American Lead Poisoning Help Association, please visit www.ALPHALead.org, email Info@ALPHALead.org, or call 609-332-6730

Learn about lead, for your child's future. Be a survivor of lead poisoning, not a victim.

New Hampshire's new lead poisoning prevention bill

On July 12, 2007, NH Governor signed SB176 into law. This new law opens the door for State health officials to take protective measures for children whose blood lead level reaches 10 µg/dL. This is one of the lowest blood lead levels to trigger State action in the United States.



NH Governor Lynch after signing the lead bill—photo courtesy of NH governor's office

The new law allows the State to conduct an envi-

ronmental investigation of the child's home and issue lead hazard remediation orders to property owners when hazards are identified, not only to the child's home, but for all apartments within the building. The law also mandates landlord noti-

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LEAD RECALL



8/1/07—Fisher Price is recalling 967,000 plastic preschool toys made in China due to lead paint hazards. This recall includes Big Bird, Elmo, Dora and Diego characters. For more information, www.service.mattel.com or call 800-916-4498

Lead from Illinois to New Jersey: Amanda and Jayson's Stories

As more parents come forward with their children's stories, their frustrations on addressing lead help inspire other parents to share their stories. Included in this newsletter are a couple new stories that touched my heart from the new ALPHA MySpace group—<http://groups.myspace.com/ALPHALEAD>

In August 2006, Sarah learned that her almost-two-year-old daughter had extreme levels of lead; her venous follow-up was **136**. Amanda's most recent level is 25 micrograms per deciliter. Below is a blog Sarah posted on Myspace, sharing her frustrations:

I took my children to the park yesterday. Now, unlike most families, a trip to the park is well...not a walk in the park. It is a change of routine. To a child dependant on routines to function, a trip to the park is a HUGE ordeal. The trip went really well, until it was time to leave. She started to get upset. I got the other 3 kids buckled in the car, and then I saw the tell-all eye flutter. See when my daughter gets over stimulated, she can't function like an "average" child. She'll get a eye flutter. Then she either withdraws or over reacts to the stimulus. This time she over reacted by running from me. As I chased my 2 year old up slides, across monkey bars and through tubes, I got "the

look" from some parents sitting on the park bench. "The look"... Any autism/lead poisoning parent knows what the look is, but for those who don't, it usually contains a rolling of the eyes and a feeling of "Get your child under control you horrible parent."

Well, I finally caught my daughter. And loaded her into the car. I went to leave my head hung in shame at my daughter's actions.

Then I thought... No. My daughter has a medical condition. Would they roll their eyes at a blind child or a child in a wheel chair?

What you DIDN'T see, was the 6 days we spent in the Children's hospitals getting shots every 4 hours praying she'd live...

So I walked up to the Mom's on the bench and said "Yes, you saw my daughter misbehaving. What you DIDN'T see, was the 6 days we spent in the Children's hospitals getting shots every 4 hours praying she'd live, You didn't see the horrible bruises those shots left on her beautiful legs. You didn't see the countless Dr's visits. You didn't see the therapy visit this morning where she finally learned how to put that puzzle together. All you can see is a child misbehaving... I wasn't going to say anything to you. I was going to leave ashamed. But I am NOT the one who should be ashamed of my daughter's behavior. She is a child with a medical condition. YOU are the ones that should be ashamed. But I will forgive your ignorance, because my daughter has taught me patience. My daughter, that you rolled your eyes at, has taught me NOT to judge others because I may not know their whole story."

I am new to the world of "autism parenting" since my daughter was not born with her condition, but I am NO longer going to sit quietly. Don't accept those looks any more. Let's educate the world... If it has to be one parent on a park bench at a time then so be it!

Leana from New Jersey shares her son Jayson's situation:

Three years ago I found out my son had lead poisoning. Right now he's 6 years old. His levels then were at 68. He was very irritated and hyper. He just wasn't himself. He was hospitalized for 1 week, they were giving him Chemet. They told us they wouldn't let him leave until we found somewhere else to live. So the lead inspectors went to my mother-in-laws house and it was cleared. We moved in and continued the Chemet. We were living there for 2 months. Once he was off the medication, his levels went up again. The docs said they thought he was being exposed again. Well we moved to our own place. It was cleared from lead. We had changed his diet, we even went to a naturopathic doc. But nothing worked. Tried the Chemet again, his lead was in the 40's. It dropped to 9. Once he was off it, it slowly climbed back into the 20's. It's been at 28 for the past year. A few months ago they inspected the house we were then living in, and after them going there 4 times they finally found lead in the hallways. The landlord fixed it, but because of problems with him, we had to move.

"He just wasn't himself..."

So now we are in a new place again. His lead hasn't dropped yet; it's only been 1 1/2 months so were hoping that it will drop soon. In the meantime we continue with a healthy diet, and giving him vitamins. I'm just hoping that what I am doing will prevent any further damage to him. Jayson is doing well in school so far, but he was only in Kindergarten; we'll be able to see how much he was affected by the lead probably this year or the next. So far, he's still aggressive in the way he speaks to us sometimes, and forgetful, and cries more then usual, and I guess he's just irritated by everything very easily.

Moms who are reading this please take your child to get tested AS SOON AS POSSIBLE. This is very preventable. Get your homes tested too. For those who are going through the same thing I am, just keep your head up. Most of us are through the worst part, some are just beginning, but we have to remember that our kids aren't victims they are survivors, we just have to stay strong for them.

News From the ALPHA Network

On April 23-27, the National Indoor Environmental Health & Technologies Conference met in Orlando FL. ALPHA parents Liz Colon (RI), Sandra Roseberry (ME/NH), and Leann Howell (NJ) each presented at the conference. Liz discussed the repercussion one year after the monumental lead paint lawsuit. Sandra presented on addressing cultural differences with at-risk populations. Leann discussed the role of parents in addressing lead poisoning and how to involve parents



Sandra, Leann & Liz in Orlando, April 2007

in ALPHA. A couple hundred ALPHA newsletters were distributed throughout the conference.

Done Testing in Iowa!! After 4 years of testing, Brenda's son Sean's lead levels were back to back under $10\mu\text{g}/\text{dL}$...we are finally done. We went to the lab this week to tell his lab techs in person; a couple of them cried over our good news. Most have watched Sean grow up these past 4 years. So this



Sean's (on right) initial lead level was 40.

was very emotional to them as well. They were recalling the day Sean turned 5 and told him, "5 year olds don't cry having blood taken"... that was the day he stopped crying during the blood tests. Now, at age 7, he says..."it's JUST a needle, no big deal."

Baby Pen arrival—On July 6, 2007, Srey gave birth to a bouncing baby girl in Tennessee. Eva weighed in at 6 pounds, 11 ounces and twenty-inches long.



Mikey Joyner is 17 and driving!!! He may also be presenting in Charleston in 2008 on lead as a poisoning survivor. Kristin is thinking about getting some of the older leaded kids to begin speaking at the conferences and possibly making a semi short film about where they are now and what they contemplate their futures as being. It would be great to get some of the kids from a large city who have already run into trouble with the law, have their moms speak out, and then have some kids who have overcome the issue. She can be reached at ducksheperd@netscape.com

Passing—On June 18, 2007 Paul Flynn, known as the Leadie Eddie spokesman for Gateway Northwest MCHN in Newark, NJ, died of congestive heart failure. Paul's contributions to end childhood lead poisoning will not soon be forgotten, throughout NJ and the US.



www.ALPHALead.org

<http://health.groups.yahoo.com/group/ALPHALEAD/>

<http://groups.myspace.com/ALPHALEAD>

Learn what's going on in lead as it happens...

The ALPHA Report is published quarterly. If you are interested in receiving more information or getting on the mailing list, please email info@ALPHALead.org

Please feel free to make copies of the newsletter & distribute in your communities.

New Hampshire's lead poisoning prevention bill

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fication of a lead poisoning at a blood lead level of $7.5\mu\text{g}/\text{dL}$, and creates a study commission of 26 stakeholders from parents and property owners, to health and housing advocates and the NH Attorney General. The commission will under take the task of researching best practices in childhood lead poisoning and the means of funding future lead poison-

ing prevention initiatives. The new law also creates a designated fund for accepting donations to enhance lead poisoning prevention strategies. This bill is the first major lead poisoning prevention bill passed in NH in over a decade and moves the State to a more proactive role. The passage of the bill was a major victory for child health and housing advocates who banded together and worked vigilantly to make this possible.

My Hat's off to you NH, Great Job!!!

Sandra Roseberry is a lead poisoning prevention advocate who participated in the passage of this bill and has worked to successfully pass five other lead poisoning prevention laws in NH, Maine and Washington, DC. For more information on becoming active in public policy making for lead poisoning prevention, please contact Sandy at 603-312-9939 or by email at Sandy@ALPHALead.org

ALPHA

American Lead Poisoning Help Association

You are not alone anymore...

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The American Lead Poisoning Help Association (ALPHA) is a national network of parents and concerned individuals providing support for other parents who are dealing with lead in their children. ALPHA currently has parents in 22 states who are united in addressing childhood lead poisoning, and is pending incorporation as a 501(c)(3) organization. Parents need to talk with other parents to understand better the lifetime effects of lead, how to cope with the difficulties that each of these children face, and how to vent their frustrations at the situation that none of them ever anticipated.

Similar to support groups for breast cancer, muscular dystrophy, autism, etc, ALPHA intends to help link parents together. Lead poisoning is an alienating disease that leaves many parents feeling ashamed - society still projects stereotypes, and many parents keep their personal situation to themselves. ALPHA is helping parents reach out to one another, not to re-invent the wheel in each state, but to network and share experiences, materials or other support.

Upcoming Lead Conferences

October 4-5, 2007, the 2007 National Mid-Year Conference on Eliminating Childhood Lead Poisoning, Conducting Healthy Homes Programs, and Providing Lead-Safe Housing in Philadelphia, PA. Opening symposium speakers include:

Jay Schneider, PhD. Thomas Jefferson University & Thomas Jefferson Medical College will present on "Understanding



Lead's Effects on the Brain: The Basic Neuroscience Perspective"

Bruce Lanphear, MD, MPH, Cincinnati Children's Hospital Medical Center will present on "The Lingering Legacy of Lead Toxicity"

John Rosen, MD, Montefiore Hospital & Medical Center, The Albert Einstein College of Medicine will present on "Medical Management of the Lead Poisoned Child"

Richard Canfield, PhD, Cornell University College of Agriculture and Life Sciences will present on

"Lead Exposure and Cognitive Function in Young Children"

April 1-4, 2008, the Indoor Environmental Health & Technologies Conference will be held in Charleston, SC.

Parents interested in attending either conference, please contact Leann for registration information at Leann@ALPHALead.org, or contact the conference hotline at 1-800-590-6522 or www.leadmoldconferences.com

National Childhood Lead Poisoning Prevention Week is October 21-27, 2007