## ADVOCACY

The LOST BOYS & GIRLS:



BY LORI MCILWAIN

# HOW AMBER AND SILVER ALERT SYSTEMS ARE FORGETTING AMERICA'S CHILDREN WITH AUTISM

s the warmer months roll in, so do summer camps, open windows and flimsy screen doors. Longer recesses in the late school months. More outdoor gatherings. More chances for a child with autism to wander.

It's only logical that an increase of disappearances and deaths would happen in our community. With 1 in 150 children now diagnosed, and 92% of them prone to wandering according to an online survey conducted by the National Autism Association, children with autism are at more risk for wandering-related deaths than ever. But if you think the AMBER Alert system will help recover our missing children, don't.

As we learned last year following the disappearance of Benjy Heil, the 7-year-old who wandered from his Michigan home, only abducted children qualify. I recall the update from a search team member: "Benjy was last seen by a neighbor on the road, the neighbor told him to get off the road or he'll get hit."... "I asked the police why they didn't send out an AMBER Alert. They said he didn't meet criteria."

It's a common assumption that AMBER Alerts are for all missing children. Named after 9-year-old Amber Hagerman who was abducted and murdered in 1996, AMBER is also an acronym for "America's Missing: Broadcasting Emergency Response." Whenever we see an AMBER Alert, we're given a description of a missing child, along with any other relevant information. In 2006, there were 261 AMBER Alerts issued, according to the National Center for Missing and Exploited Children. Children were recovered on the same day of the Alert in 106 of the cases, with the majority being found within the same city they were reported missing. Eleven of the 261 cases crossed state lines.

## COULD AN AMBER ALERT SYSTEM HELP OUR CHILDREN?

One can't help wondering if an AMBER Alert would have helped Benjy. Maybe the neighbor would have known to call 911. Benjy's body was found a few days later in a creek.

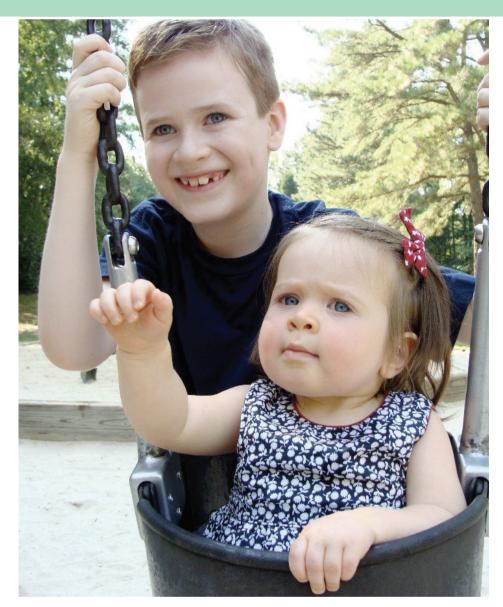
According to a study published in the Journal of Autism and Developmental Disorders (Shavelle, et al, 2001), elevated death rates among those with autism were in large part attributed to drowning. Drownings typically happen after a child with autism has wandered. In the past four years alone, at least 14 children with autism under age 12 have died as a result of wandering.

A couple of months after Benjy's death, my own child went missing. Same age, same diagnosis. He managed to escape a schoolyard – wandering close to an hour before a gentleman found him. "I almost didn't stop," the man told me. "He looked like he could've been old enough to walk alone, he was heading towards Davis Drive." (Davis, one of the busiest four lane roads in our town.) In his thick Brooklyn accent, he explained he was going to buy stamps, and although he drove past Connor, he figured he'd turn the car around to "get a better look." Once he realized Connor was missing, he called the local authorities.

That night I went from restlessly lying in bed, to sitting up. I wrapped my forearms around my knees, rocking, sobbing. Benjy Heil's mother didn't have what I had. Come dark, her child was still missing. Come three days, her child was dead.

Like any parents, my husband Christian and I fear the worst each time Connor leaves our home. He's wandered a total of seven times, each time from the classroom or playground of three different schools. We've taken detailed measures to ensure his safety, including fighting for a oneon-one and enrolling him in the Project Lifesaver program, which provides a tracking transmitter that Connor now wears around his wrist. Most Sheriff offices do not participate in Project Lifesaver due to lack of funding, so it's only available to a select few. Having an organized alert system in place would help compensate for the lack of programs like Project Lifesaver.

I've thought about Benjy from time and time, and Logan Mitcheltree, who wandered from his Pennsylvania home in 2004. He was 9-years-old and died from prolonged exposure to the cold. I've kept a well-worn







Lori's children: Connor and Charlotte

news photo of him at my desk as a reminder. Being a child advocate and part of the National Autism Association, it's children like this that instill the desire to not give up.

### A NEW ALERT SYSTEM IS CREATED, BUT NO CHILDREN ALLOWED

It was early May when I was reminded of the AMBER Alert. One had been issued in our area – the details crawled over our evening newscast. I must've let out a sigh since Christian, my husband, asked what was wrong. I explained what happened to Benjy, and how an AMBER Alert could've made a difference. He walked to the computer, looked up the AMBER Alert and wrote down the lawmakers most involved with its enactment.

I'd been down this road before. Calling

legislators. Asking their receptionist for the right staffer. Getting voicemail and a callback born out of obligation more than compassion. All reasons to procrastinate. Then a few days later I noticed a different alert on my TV screen. A Silver Alert. Although I'd never heard of it, I understood what it meant. A missing senior, likely with Alzheimer's.

The Silver Alert became effective in my state of North Carolina in 2007. It's a system that notifies the public about missing endangered adults who suffer from dementia or other cognitive impairments, such as Alzheimer's disease. The only downside to the system? No children allowed.

It prompted me to call one of the names on my list – Senator Dianne Feinstein, a California Democrat who had helped our Drownings typically happen after a child with autism has wandered. In the past four years alone, at least 14 children with autism under age 12 have died as a result of wandering.

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cause in the past. Once I got her Judiciary staffer on the phone, I figured it would be a no-brainer. "We need to expand the criteria of the AMBER Alert," I told him. "Our children need the same recovery measures as seniors with Alzheimer's, except under the AMBER Alert name. People know it's for children."

It wasn't that simple, he explained. AMBER Alert is part of a national communications system. It's for abducted children that are likely to cross state lines. He added that if too many children were included in the Alert's criteria, say, for local recovery measures, other groups would want their children added, too. Too many alerts would result in a desensitized public.

But we're talking about disabled children. Not teenage runaways. Not prom-goers that missed curfew. The staffer has since not returned my calls or emails. A faxing campaign to Feinstein's office was initiated. Feinstein replied she would keep our "concerns and suggestions in mind as my staff and I continue to review legislative options on this matter."

Kay Bailey Hutchinson, the Republican Senator from Texas where the AMBER Alert legislation originated, was the second office I phoned. Her staffer was politely dismissive while pointing out several times that I was "the first person to call about this."

### SILVER ALERT: HOW IT WORKS, WHY IT'S NEEDED

I began checking Google news searches each day for Silver and AMBER Alerts. So when the Silver Alert went into effect in Ohio in June, an article from the Springfield News-Sun happened to be the first to show. Springfield is my hometown and where my family lives, including my brother Chris, a Deputy Sheriff in Champaign County, Ohio. I called him to learn what the Alert entails. Between reading the articles and speaking to him, I learned any adult with a mental disability in Ohio qualifies, minors excluded.

Major John Newsom, of the Warren County Sheriff's Office in Ohio spoke about the system in an article on WCPO. com. "If [a senior] is reported missing, a protocol would be followed that could lead to the ARTIMIS message boards being activated and information broadcast over radios, televisions, cell phones and other communications devices." He added, "One of the reasons you want to get this information out quickly is that within the first 24-hours of a senior going missing, usually injuries and fatal injuries increase every hour ... if you get them back within 24-hours, their chances of survival and their chances of not being injured increase astronomically."

And according to Mark Patchen, technical support division director of the Ohio Emergency Management Agency, "The 'Missing Adult Alert' system provides resources and coordination between various government agencies, law enforcement, media and most importantly the public who are the eyes and ears needed to locate a missing person."

What it boils down to is this: if you're an adult with a cognitive impairment, even autism, and you go missing in Ohio, first-class recovery services are available. This includes a readymade coordinated effort among local law enforcement agencies, and public and commercial radio and television broadcasters. But if you're a minor...a 17-year-old, 4, 8, 10, 15-year-old with autism, mental retardation, Down Syndrome, Asperger's, you at best get a manually-devised search effort that could take hours to coordinate. North Carolina is similar. If you're 18 and have autism, a Silver Alert can be issued. If you're 17 and under, it cannot. If a law enforcement agency tries to issue an AMBER Alert or Silver Alert for a disabled child who does not meet age requirements or is not abducted, the request will be blocked.

"Be aware that any Sheriff can call local media anytime a child goes missing," Chris explained. "Does each office do it?" I asked. "Does the Sheriff three, four, five counties over call local media each time, and if he/ she does, do the stations air the information each time?" He couldn't say with certainly. It would be difficult to predict how each law agency and media outlet would respond, unless it's mandated. For children, it's not.

There is one state that appears to have open criteria to anyone with a developmental disability. Colorado.

Could we make it so all states follow Colorado's example?

On a side note: since Connor is part of Project Lifesaver, I frequent the program's website to look at recent recoveries. In Manassas, Virginia, a child with autism was recovered after 1 hour, 12 minutes. In Sioux County, 45 minutes. In Aprahoe County, Colorado, 2 hours. These children were gone significant amounts of time, even with a tracking device. Our children are gone long enough to warrant an alert. For the mass majority of children who are unable to have a tracking device, faster search measures could save lives.

### **OBJECTIONS TO AN ORGANIZED ALERT SYSTEM FOR AUTISTIC CHILDREN**

"Seniors are more at risk for driving across state lines," my brother explained. "We've seen it happen and this is why a Silver Alert is needed on a national level."

But how often does it happen? How many adults with mental retardation possess a driver's license? More often than not, disabled adults that go missing will stay local just like children with autism. And of the dozens of issued Silver Alerts, I've not found one issued in a secondary state.

Are we basing an exclusion of our most vulnerable members of society on the possibility of seniors driving across states lines? That's not good enough. Our children may not drive, but they face other immediate dangers, like water. And our children are more at risk for being abducted after wandering off, ironically.

Don't take my points as opposition to the Silver Alert system. I should note I have an aunt that suffers from dementia. Seniors need the system. I'm relieved that our adults with autism qualify for the Alert in certain states. Why can't children have it too?

Although my brother provided constructive viewpoints, he ultimately agreed an organized alert system for

children with cognitive impairments would be helpful in their recovery, especially for those that appear old enough to walk alone. He was in favor of an additional alert system specifically designed for them.

## THE NATIONAL SILVER ALERT ACT WON'T INCLUDE CHILDREN

In May, Congressman Lloyd Doggett (D-Texas) introduced the National Silver Alert Act to create a voluntary national system to protect missing senior citizens with dementia. Administered nationally by the Justice Department, the program would authorize up to \$10 million in grants to states to develop, maintain and coordinate Silver Alert programs.

Doggett staffer Mike Williams spoke to me at length about the legislation. "Can't The Silver Alert expand its criteria to include children, at least until another option is available?" I asked. "It would be up to the states," he replied. But when I asked if Doggett's federal bill would encourage states to include minors in the criteria, I was told he would have to check with his "boss" and get back to me. I've not heard from him. If you read Doggett's legislation, the word "senior" is used throughout – far from encouraging states to include children. In any case, following Colorado's lead on a national level seems like the wisest option, at least until a specific alert can be put in place for our children, if ever.

## IMMEDIATE AID FOR OUR MISSING CHILDREN?

Criteria expansion in Silver Alerts or similar bills may be possible in states where it doesn't already exist. Five more states are considering Silver Alerts, including Louisiana, New Jersey, Pennsylvania, New York, and Rhode Island. Silver Alerts are already in place in Colorado, Georgia, North Carolina, Ohio, Texas and Virginia.

In Michigan, where Benjy Heil died, Congresswoman Candice Miller pledged her recent support of the Silver Alert. A local paper quoted her as saying, "The AMBER Alert System works and it works well. Our seniors deserve no less support, particularly those suffering from Alzheimer's or dementia." Congresswoman Miller's statement implies children suffering with similar cognitive disabilities fall under the AMBER Alert's support. It's uncertain how many other legislators, although well intentioned, are making the same mistake.

Nevertheless, it is my hope that lawmakers will work to create something soon for disabled children. Until then, many more will likely have to die before an organized alert system is considered.

## WHAT YOU CAN DO

If you live in a state where the Silver Alert may take effect, write your legislators and ask that children with cognitive impairments be added to the Alert's criteria at least until another option is available. This especially holds true if you live in an area where an autistic child has died from wandering.

If your child is prone to wandering, a complete list of safety tips can be found on the National Autism Association web site at www.nationalautismassociation.org/safetytoolkit.

For related questions or comments, please write **lori@nationalautism.org**.

## To qualify for an AMBER Alert, a missing child must meet the following guidelines:

- Law enforcement must confirm that an abduction has taken place
- ✓ The child is at risk of serious injury or death
- ✓ There is sufficient descriptive information of child, captor, or captor's vehicle to issue an Alert
- The child must be 17 years old or younger

## To qualify for a SILVER Alert, the missing person must meet the following state guidelines:

#### Georgia

- Disabled adult
- Believed missing
- In immediate danger or serious injury or death
- ✓ Sufficient information exists to engage the public's help

## North Carolina

- 18 years old or older
- Suffering from dementia or other cognitive impairment
- The person is believed to be facing potential harm

## Ohio

- The individual be in danger, faces a credible threat
- ✓ Age 65 or older
- ✓ Mentally impaired
- Reported missing
- A temporary or permanent resident of the state

## Colorado

- ✓ Domicile in Colorado
- Has a verified developmental disability
- Disappearance poses a credible threat to their safety

## Texas

- 🗸 65 or older
- Domiciled in TexasHave Alzheimer's, dementia
- or another mental impairment
- The disappearance poses a credible threat to the person's health and safety
- ✓ Silver Alert must be requested within 72 hours of the person's disappearance
- There is sufficient info for the public to help

#### Virginia

- Has a cognitive impairment which prevents him/her from caring for himself without the assistance of a caregiver
- ✓ 60 or older
- The disappearance poses a threat to the health and safety of the senior