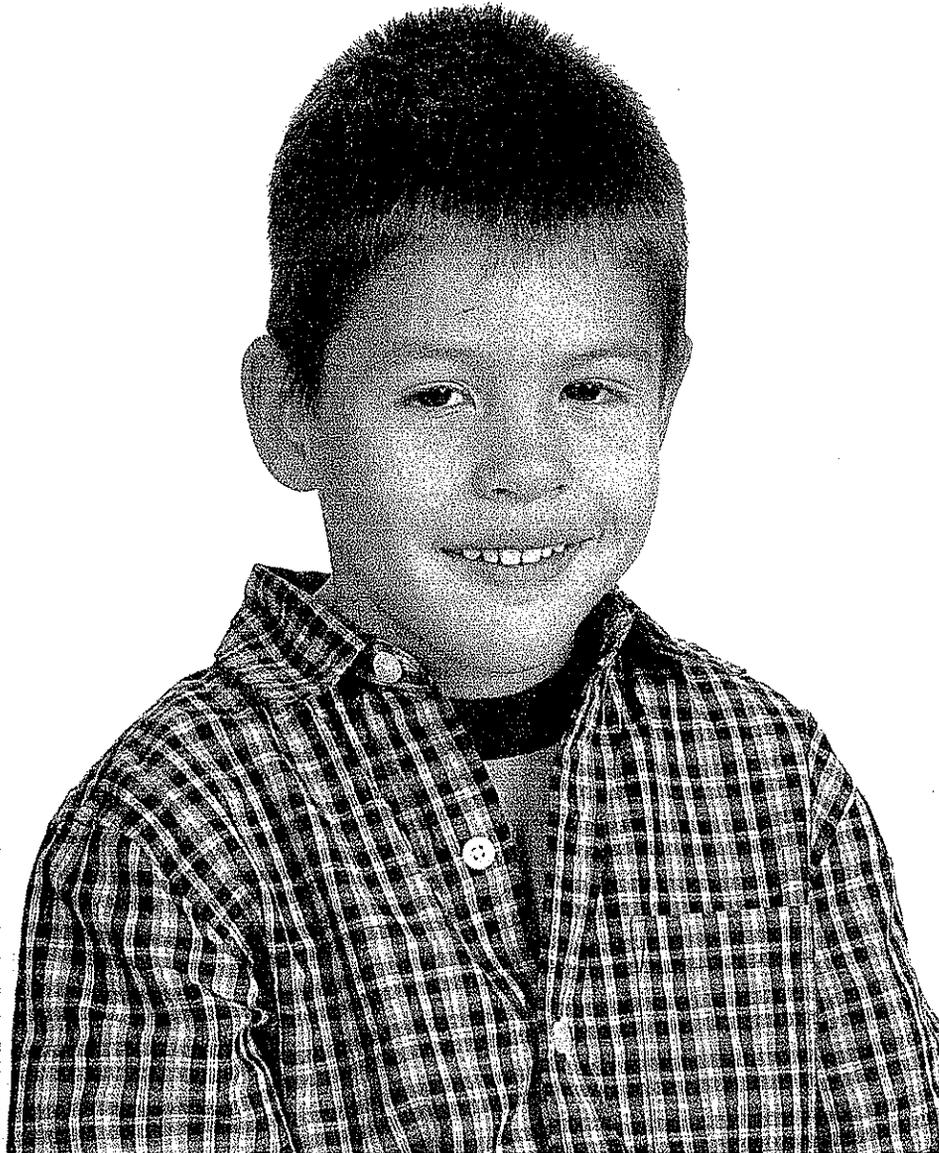


Proposed Bill #6110 AN ACT INCREASING AWARENESS ABOUT ALTERNATING HEMIPLEGIA IN CHILDHOOD.

AHC (www.ahckids.org) is a rare neurological disorder in which repeated, transient attacks of hemiplegia occur, affecting one side of the body or the other, or both sides of the body. The hemiplegia (paralysis of a portion of the body) ranges from simple numbness in an extremity to full loss of feeling and movement. The attacks may last for minutes, hours or even days. The attacks of hemiplegia may alternate from one side of the body to another. Some Children with AHC have exhibited a wide range of symptoms in addition to AHC. These include tonic attacks (lack of muscle tone), dystonic posturing (stiffening of extremities), nystagmus and other oculomotor abnormalities (eye disorders), developmental delays, mental retardation and seizures. **Less than 300 people in the world have been diagnosed with AHC.**

Oga A. Gerber



Proposed Bill #6110 AN ACT INCREASING AWARENESS ABOUT ALTERNATING HEMIPLEGIA IN CHILDHOOD.

Sean E. Gerber afflicted by Alternating Hemiplegia of Childhood since birth.

My son Sean was born four years ago after a perfect pregnancy. He was 9lbs, 3oz, 21" at birth. The next day he was admitted to the NICU for a week because a nurse thought he had a seizure. He had many tests done during a week stay at the NICU. The tests consisted of a CT Scan, MRI, EEG, Spinal Tap and metabolic testing. All tests came back proving he was fine. I continued to see abnormal eye movements and arm tremors for the next two months. When he was almost 3 months old, we went out to breakfast on a Sunday morning and Sean went into full body dystonia. He was so stiff he could not be placed in the car seat. That was the first of 13 ER trips to CT Children's Hospital in Hartford. There were many repeated EEGs, CT Scans, MRIs, Spinal Taps and Metabolic testing. We were in and out of the hospital for days and weeks at a time for a year because he continued to have spells. We went to Yale New Haven Hospital for a 5 day telemetry observation for a second opinion. This consisted of Sean having an EEG attached and surveillance with a camera 24 hours a day. Again, he was misdiagnosed at Yale. At one year old, after many medications and tests ran, he was diagnosed with Alternating Hemiplegia of Childhood (AHC) by a 3rd opinion at Boston Children's Hospital after another 5 day telemetry observation. During Sean's first year of life, he was placed on 13 different medications. This does not include the ones he was given in the ER and the hospital admissions.

The attacks vary with each person. Sean's attacks were so diverse and bizarre that we had to video tape him for the doctors to believe what we were explaining. An attack on Sean will consist of one eye going side to side, both eyes going up and down at the same time, being paralyzed in one arm or a leg or both arm and leg and sometimes it will affect him from head to toe. An attack can last from a few minutes or even days. After each attack, it takes him a day or two to get back to the milestones he had accomplished. He is developmentally delayed. He walks off balanced as if he were just learning to walk. He is not coordinated enough to use utensils and needs assistance in eating his meals. His speech is severely delayed. The amount of attacks a child has will affect him/her mentally and physically. **There is no known cause or cure for AHC.** We do not know what triggers the attacks.

July of 2005, we attended an AHC Conference in Boston with about 30 other families and were able to see other children between the ages of two and 24 years old that also suffered from AHC. Every child was affected differently, some more severe than others. Most of the children over five years old, had wheel chairs or some type of adaptive device to help them get around. Many of the children wore sun glasses because light bothered them, some drooled more than others, some spoke better than others and some were more socially apt. This was a depressing view of Sean's future as **AHC is a degenerative disorder.**

After all the medical professionals we saw and all the things the doctors thought he may have had, we really believe there are more children/people with this disorder and are misdiagnosed. Not many people, including physicians, have heard of AHC. The Journal Inquirer (February 27, 2006), South Windsor Life (May 06, Volume 5, Issue 8), The Hartford Courant (May 5, 2006) and Fox 61 News (Special Assignment May 4, 2006) supported our family and AHC by helping expose the disorder. We hope that the medical professionals become more educated on AHC so that children and families do not have to suffer through the same repetitious and meaningless testing and endure the pain our child and our family have experienced.

Thank you,
Sean E. Gerber

Proposed Bill #6110

Dear Health Committee Legislators:

Sean Gerber has been a student in my special education preschool classroom for the past 2 years. As a child with Alternating Hemiplegia of Childhood (AHC), Sean has many daily challenges that affect his education, socialization, independence, communication, and physical abilities. Depending on Sean's status, his functioning can range from moderately impaired, to 100% dependent on others.

Sean currently receives 10 hours per week of special education preschool year-round, including speech and language, occupational, and physical therapies. Due to his unpredictable altering states of functioning, it is often difficult to plan and implement consistent education for him. In addition, Sean's safety is an ongoing concern because of his poor motor coordination, impulsivity, and delayed cognitive processing. Sean also has behavioral concerns, a significant communication impairment, and is not able to complete most self-help tasks, such as washing his hands, toileting and dressing without assistance. Sean's challenges that I observe in the school environment are only a snapshot of those he and his family face throughout each day.

AHC is a neurological disorder that significantly affects a child's global functioning. It severely impacts the individuals with the disorder, their families, and their communities. Due to its unpredictability and transient episodes, as well as the lack of research, many doctors are not familiar with AHC and it has the potential to be misdiagnosed. In listening to Mr. and Mrs. Gerber's recollections of their heartbreaking struggles to find out what their son was suffering from as an infant, it is clear that doctors should be required to have knowledge of AHC. In addition, as Sean has entered the public school system, I as an educator am disappointed by the lack of knowledge about AHC by pediatricians, neurologists and neuropsychologists; their lack of knowledge results in a lack of guidance for educators and school medical staff.

It is hoped that with growing awareness of AHC other families and individuals will have less of a struggle to find answers, support and guidance. Through research, improved early diagnosis, and reduction of misdiagnoses, more children with AHC will be provided with early intervention, families will be provided with more appropriate support, and communities will be able to better prepare for these children in the school systems, community life, and adulthood. This process can begin by assuring that all doctors have knowledge of Alternating Hemiplegia of Childhood.

With appreciation,

Dana N. Ballou, Special Education Teacher
South Windsor Public Schools
[danapop12@yahoo.com]

Proposed Bill #6110 AN ACT INCREASING AWARENESS ABOUT ALTERNATING HEMIPLEGIA IN CHILDHOOD.

Alec is 8 years old now and started to show AHC symptoms at 2 years 10months old.

He started off with a high fever and not being able to get off the couch (full body episode) this went on for one week. Doctors assured us he had the flu and was fine. He ended up in the hospital unable to walk or speak the same.

From this point on he had periods of "episodes" that looked like small seizures. His eyes would roll in the back of his head, his color would change grey, he would start to drool, and his feet would flap along with slurred speech and large bumps on his head. He would also get left side facial droop and paralysis.

At this point the doctors were convinced that he had epileptic seizures. He was in the hospital time after time having countless EEGs that showed nothing. He had Cat Scans, MRIs, MRAs, spinal tap, blood work, all showing how perfectly healthy he was yet he kept having these "episodes" of seizure looking things that kept making him lose his milestones and become less healthy and less normal.

Finally, Alec was put in to Children's Hospital in Boston for a week long work up which included observation, blood work, genetic work up and a pet scan which resulted in a diagnosis of Alternating Hemiplegia of Childhood.

Alec's diagnosis took six months to get. He was in and out of the hospital, poked, looked at and examined so many times I lost count. We were lucky that the study of AHC was at Children's Hospital Boston so the doctors were familiar with it. Because of this the 6 month time frame is short considering what other families go through.

Respectfully,

Kelly Costedio

Proposed Bill #6110 An Act Increasing Awareness about Alternating Hemiplegia of Childhood.

How do I convince you to pass this bill? How do I make you understand that there are more children out there with Alternating Hemiplegia of Childhood (AHC) whose doctors and parents don't know the disorder exists? How do I make you understand that every minute does count for these children? These children are repeatedly being misdiagnosed with various forms of epilepsy, meningitis, cerebral palsy and more. Each time these children have an episode that is not properly treated they face potential brain damage. It sounds extreme, but that is exactly what happens. These kids need treatment and many need to have their episodes stopped by inducing sleep via medication. The sooner they are diagnosed, the sooner treatment can begin and the damage to the brain can be stopped and/or decreased. The fewer episodes a child has, the more opportunity their brain will have to develop normally. Pediatricians are the first stop for these children and their ability to recognize the signs and symptoms of AHC could mean the difference between a life spent in a wheelchair with very little cognitive function or a fairly normal life with only minimal physical and/or cognitive challenges.

My son, Ian, was lucky that his neurologist knew of the illness because no one else did. Initially, a covering pediatrician thought it was the flu. The following day Ian's regular pediatrician agreed that something was wrong, and even stated that he thought it was neurological. He sent us to Connecticut Children's Medical Center (CCMC) where Ian was seen by many ER doctors who said it was just the flu and refused to call the neurology dept. They sent us home. The next day we went back to Ian's pediatrician and he called CCMC and requested that Ian see a neurologist. Back we went, and the ER doctors were still talking about the flu until the neurologist arrived – then things finally started to happen.

Ian's first diagnosis was meningitis, an inflammation of the brain caused by an unknown virus. Ian was discharged after a week and it took him months to regain skills and abilities that he had lost. In June of 2005, Ian had his second episode and once again we were back at the CCMC emergency room. The ER doctors told us it was a concussion (Ian had a history of falling and concussions that were later attributed to AHC) and that we should take him home. We told them we wanted him admitted, because we knew something wasn't right. Ultimately, Ian was admitted and Dr. Dimario tentatively diagnosed him with AHC.

My son's most recent episode, in September of 2006, required a trip to the emergency room. At the hospital I told the nurse about his illness and what needed to be done. The look on her face was not of acceptance, but of disbelief and disapproval. She told me she had never heard of such a thing and practically scoffed as she said it. The doctor came in next and was a bit more receptive. That said, I still had to convince him that medicating my son was the right thing to do and that it needed to be done fast. I asked him to call my son's doctor who would verify this. Instead he told me he thought it best to wait and see if my son acted up again! I immediately ran to the public phone to call Ian's doctor. From where I stood, I could see the ER doctor Googling AHC! I spoke with Ian's doctor's office and shortly thereafter the ER doctor came into my son's room and told us that he would sedate him. I can only surmise that he spoke to Ian's pediatrician, but I didn't stop to ask questions because Ian was getting worse. Ian was sedated and the disapproving nurse returned to Ian's room with a completely different attitude. In fact, she asked us to tell her all about the illness and she reiterated that she had "never heard of anything like it".

About a month later, Ian developed a small rash on his head. Ian's pediatrician was ill so we saw a covering doctor. Ian was still recovering from the previous episode and was limping and not using his left arm. The covering doctor quickly diagnosed his rash and then commented on Ian's unusual posture and walk. I told him about Ian's illness and he sat there, temporarily speechless. He said he had never heard of the illness and then starting asking questions.

As you can see, it is the exception, rather than the norm for a medical provider to have ever heard of AHC, let alone recognize some of the key symptoms. One only needs to listen to the AHC families to find stories of children who were believed to have other illnesses until they were properly diagnosed.

We sincerely believe that Ian's early diagnosis has given him a better chance to develop more normally and that without it he would have had additional physical and cognitive losses. Please help us to give other children that same chance. Time truly is of the essence. Please help us to educate the medical community so that these children can be diagnosed and treated now.

Thank you for your time and consideration.

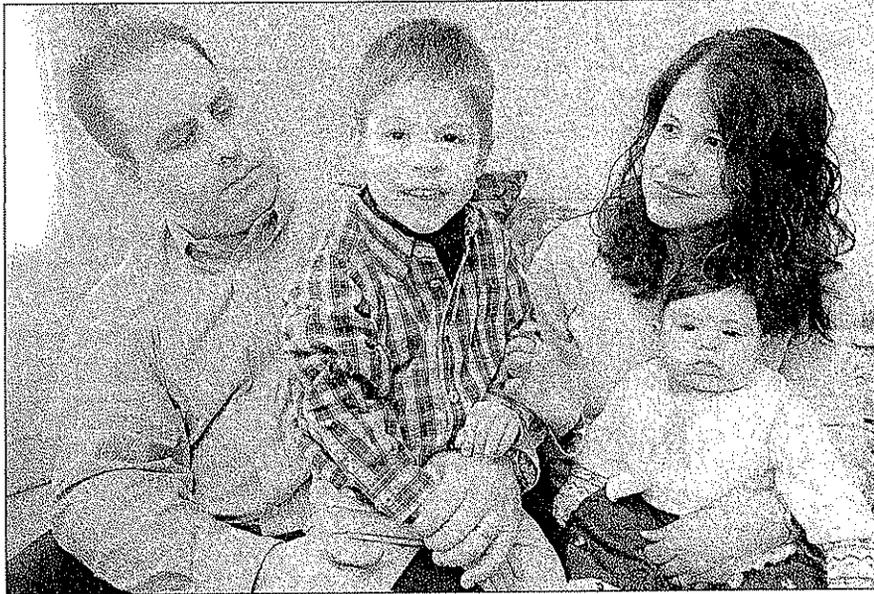
Paula Couture-Palmerino
290 Exeter Road, Lebanon, CT 06249, 860-642-7124, gpalmerino@sbcglobal.net

**Proposed Bill #6110 AN ACT INCREASING AWARENESS ABOUT
ALTERNATING HEMIPLEGIA IN CHILDHOOD.**

Neurologist, Dr. Michael Krinsky, Pres. Hartford Co. Medical Association

On Fox 61 News at Ten Special Assignment, Dr. Krinsky stated a lot was unknown. Dr. Krinsky said "the area is pretty muddy at this point despite the fact it is 2006 but research is being done and most specifically in the genetic characteristics of the disorder and the answer may lie somewhere in that."

Health & Medicine



Jim Michaud / Journal Inquirer

William and Olga Gerber with Sean and baby Shelby

Family fights rare neurological disorder

By Jennifer Hoyt
Journal Inquirer

For now, Sean Gerber of South Windsor is a playful 3-year-old who just wants to "wrestle all the boys and kiss all the girls," as his mother likes to say.

Although he suffers from a rare disorder that causes him to have frequent neurological attacks, his parents, Olga and Bill Gerber, say they consider these years the easy time, before the disorder causes his mind and body to deteriorate further.

For the first years of her son's life, Olga had trouble accepting that Sean probably won't recover from Alternating Hemiplegia of Childhood. The disorder involves frequent attacks of hemiplegia, meaning paralysis striking different parts of the body. It also can cause muscle spasms.

"I keep thinking there'll be a miracle, and he'll be fine," his mother says.

But accepting Sean's disorder has led his parents to action instead of resignation.

The Gerbers are planning a dinner-dance to raise money for research on the disorder and public awareness of it.

The dinner-dance, to be held May 5 at Maneeley's Banquet Facility in South Windsor, will include raffles and a silent auction.

The Gerbers have sent out hundreds of invitations to doctors, friends, and hospitals. They are asking local businesses to sponsor tables and to make donations to the event's silent auction.

The money raised will go to the Alternating Hemiplegia of Childhood Foundation.

The foundation says the cause of the disorder hasn't been determined, and there is no cure.

There is no proof that the disorder is fatal or shortens life expectancy. But there is developing evidence that it "may cause ongoing mental and neurological deficits with a progressive course," according to the foundation.

The Gerbers say they want to raise awareness about the disorder so that others don't have to go through the frustrating process they did, when no one could determine why their son was having the frequent attacks.

The disorder is so rare that Sean was repeatedly misdiagnosed in the first year of his life. Finally a group of doctors in Boston realized he was one of the 100 people in the country suffering from the disorder.

The hardest part of dealing with the disorder is its unpredictability. There are no clear triggers for the sporadic episodes, which can last anywhere from a few minutes to two weeks, affecting Sean differently

each time.

When doctors didn't believe their accounts of the episodes, the Gerbers made a video that shows many of the attacks Sean has suffered through.

In some clips he is in obvious pain, frustrated that he can't control his body, as one of his limbs stiffens or his eye experiences spasms. But in others, he looks patient and pensive, even trying to keep playing with a rattle while his eyes roll uncontrollably up and down in their sockets.

Two genetic tests have shown that the disorder isn't hereditary in Sean's case.

"It's just a fluke," Olga said.

Five months ago, Sean's sister Shelby was born without the disorder.

Sean attempts to lead a normal life, quickly picking himself up after his frequent falls and trying to walk during attacks, even when he knows that one of his legs is temporarily paralyzed.

His speech is impaired because of the disorder, but he proudly speaks the words he does know, like "cheese" when he sees a camera and "hair" when his mother touches his head.

He loves going to Eli Terry Elementary School four days a week. He has made many friends at school, and his teachers are learning to handle his attacks, Olga said.

Last summer the Gerbers attended a conference for children with the disorder, hoping to find comfort and advice from other families in their situation.

Yet Olga and Bill still shudder when thinking about the conference, where they witnessed how much Sean's mental and physical capacities are likely to deteriorate.

Bill said he regrets going to the conference because "blindness is a better way to go sometimes."

The Gerbers are watching Sean's growth with nostalgia and fear because they realize that the closer he gets to puberty, the more his mental and physical abilities are likely to decline.

The fundraiser is their way of fighting the helplessness they feel.

"You can't look back and say you didn't do anything," Bill said.

"You have to push and push and do all you can because you're all they have," Olga said of her children. "You will never know true love until you have a child."

Those who wish to buy tickets or make a donation to the fundraiser can call Olga Gerber at (860) 680-9410. Donations can be sent to the Alternating Hemiplegia of Childhood Foundation, 173 Wind-sorville Road, South Windsor, CT 06074.

Push to find out sooner when cancer spreads to the brain

By Lauran Neergaard
Associated Press

WASHINGTON — No one ever checked whether Leslie Bather's breast cancer was spreading to her brain, until the day tumors caused three frightening seizures. MRI scans can help spot when cancer in another part of the body sends seedlings into the brain, but few patients get routine checks.

Neurology specialists say it's time to change that: More patients are surviving initial tumors long enough for their brains to be at risk, as treatments get better at battling cancer below the neck yet fail to protect the brain. And improved technology is making it easier and safer to treat those new brain tumors, if they're caught early.

"If I were diagnosed with cancer tomorrow, the first thing I'd want is a brain scan," says Dr. Leonard Cerullo, director of the Chicago Institute of Neurosurgery and Neuroresearch.

This type of brain cancer "is becoming a bigger and bigger clinical problem," adds Dr. Frank Lieberman, neuro-oncology chief at the University of Pittsburgh Cancer Center.

Already, about 150,000 Americans a year are diagnosed with what is called a "metastatic brain tumor" — cancer that spread into the brain from some other part of the body.

Any cancer can spread to the brain. But lung cancer is the leader; it will happen in up to 40 percent of lung cancer patients, often very early in their disease. Up to a third of breast cancer patients will experience a brain metastasis. Also common spreaders are melanoma and kidney and colon cancer.

Not too many years ago, doctors mostly discovered metastatic brain cancer when its victims already were close to dying from tumors riddling other parts of their bodies.

Now, breast specialists in particular are reporting an increasing number of women who beat back cancer elsewhere in the body, only to have it flare in the brain. It seems to be a special concern among users of Herceptin, a powerful drug that targets an aggressive type of breast cancer — everywhere except in the brain, because it's too large a molecule to penetrate the blood-brain barrier, explains Lieberman.

But it's a more widespread concern. While the American Cancer Society doesn't yet have a count of the reported increase, it notes that cancer patients overall are living longer, providing more time for microscopic tumor cells incubating in the brain to take root.

Scientists are beginning to fight back:

- Studies are under way to see if an experimental drug called lapatinib, made by GlaxoSmithKline, can treat breast cancer that spreads to the brain. Lapatinib targets the same aggressive breast cancer as Herceptin does but is thought to easily penetrate the brain.

- Also under study is whether some commonly used cancer drugs could ever cross into the brain, especially if used in conjunction with brain radiation.

- And neurology specialists are urging general oncologists to start checking patients, especially those with lung or breast cancer, for spread to the brain well before symptoms appear.

There are no formal guidelines, but at Pittsburgh, MRI scans — not

Up to a third of breast cancer patients will experience a brain metastasis.

CT scans that Lieberman calls less sensitive in the brain — are being incorporated shortly after original diagnosis. After that initial scan, Chicago's Cerullo advises including the brain in any routine check for cancer spread. He says insurance generally pays.

High doses of whole-brain radiation once were the only treatment for metastatic brain cancer, and could cause such troubling side effects as memory loss, Cerullo says.

Now, treatment is more sophisticated, especially for tumors caught early. Topping the list: radiosurgery, using focused beams of radiation to zap just the cancerous cells and not surrounding healthy brain tissue. Whole-brain radiation today comes in safer doses with fewer side effects, but when to use it is controversial. Some studies suggest a preventive course could protect certain lung cancer patients, for example.

Lieberman and Cerullo advise patients to ask about a brain scan. It's advice that Bather, the Chicago patient, echoes. She calls her 2004 seizures "definitely divine intervention" because only then did she get a brain scan — even though tests that same week had found breast cancer spreading in her lungs and liver.

"You want to think you're OK," says Bather, 52, whose brain seems clear after treatment of more than 40 tumor sites, but she still is battling cancer elsewhere. Instead, "what you don't know can hurt you."

Neighbors

Support research on a rare condition

Family copes with son's devastating illness

by Jan Tarr

On the outside, the Gerbers look like a typical suburban family. A beautiful mom, a good-looking dad, two adorable children — boy and a girl. Play equipment in the backyard. A “workbench” with “tools” in the living room and a “kitchen” in the downstairs family room.

Then Bill Gerber shows the videos of Sean, who will be four in June. Here are shots of a baby boy who stiffens and cannot be moved. Another shot shows him unable to focus one eye. Here he is as a toddler standing pretty much on one foot because his other leg can't hold him. He can wave with one hand but the other hand and arm hang useless. Sean looks similar to someone who has had a stroke. This particular day is a good one, his mother, Olga, said, as the youngster bounced around the living room, his gait off balance. The family never knows when the dark-eyed boy will have an “episode.”

He has something called alternating hemiplegia of childhood. Never heard of it? It's very uncommon. The Children's Hospital, Harvard Medical School's web site has an article written in 2000 from pediatric neurology that says the hospital has seen 44 cases. Mrs. Gerber, who works in human resources for the state, said fewer than 300 known cases have been diagnosed in the entire world.

With so few victims, little money is directed toward research to find causes, never mind a cure. To raise awareness, at least locally, the Gerbers are having a silent auction dinner dance at Maneley's on May 5, beginning at 6:15 p.m. Gift certificates for spas, brick work, retail stores; gift baskets, sports collectibles, gifts from a jeweler and Hartford Stage Co. tickets are among the dozens of auction items that

Olga Gerber holds Sean as he grins for the camera. Bill Gerber holds Shelby, 7 months.

Sean has a rare disorder called alternating hemiplegia of childhood.

have been donated. Mrs. Gerber said several companies, both locally and out of town, have taken a table as well as made donations. Proceeds go to Alternating Hemiplegia of Childhood Foundation. Tickets are \$40. Don Anderson is the DJ.

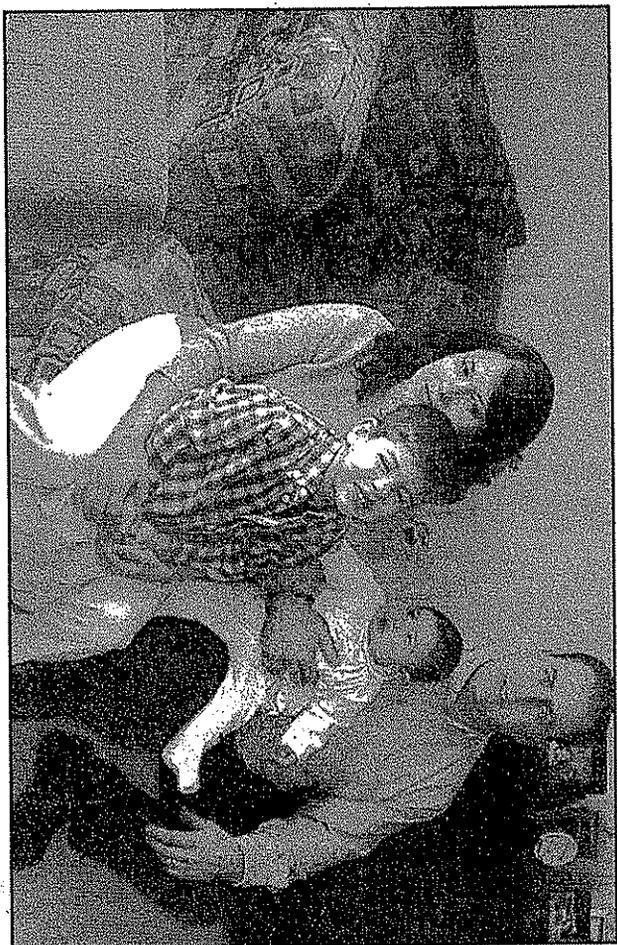
Mrs. Gerber said information about the condition is to be available but mostly she wants people to come for a good time.

Day after birth

After what she calls a “perfect pregnancy,” Sean was born weighing, 9 lbs., 3 oz. and 21 inches long. The next day he was admitted to the neonatal intensive care unit because a nurse thought he was having a seizure. After numerous tests he was declared “fine” and the family went home. Although Mrs. Gerber said she saw “abnormal eye movements and arm tremors for the next two months ... We didn't want to acknowledge” anything was wrong.

But when he was three months old, there was no denying it. They were out having breakfast on a Sunday morning “when he stiffened from head to toe. We couldn't bend anything on him.” They couldn't even get him in his car seat.

“It was so scary. You can't imagine. You don't have Parenting 101 class on all this. We didn't know what was happening.” So she sat in the back seat with him while Mr. Gerber sped to Connecticut



Children's Hospital in Hartford.

He said, “I thought what was more scary was when we got to the hospital. They didn't know” what was wrong.

The Gerbers then went to Yale-New Haven Hospital. All tests kept coming back “normal” but Sean “was on so many medications” for conditions such as seizures. His symptoms were so varied, “We started taking the videos so doctors could see we aren't crazy,” Mrs. Gerber said.

Finally the family ended up at Boston Children's Hospital where Dr. James Rivello, head of neurology, put a name on Sean's problems. They started contacting foundations and searching the Internet for information.

Alternating hemiplegia is a rare neurological disorder in which repeated attacks can occur, affecting one side of the body or both. The paralysis ranges from numbness in an extremity to full loss of feeling and movement. It can develop any time up to four years old.

Dr. Rivello said, “We've seen quite a number of them here. One of the doctors had seen a case and set up a registry, collected data from all over the world. It is very rare. I would bet you that most neurologists have never seen it or not recognized it.” The Gerbers have never seen it or not recognized it. “The Gerbers experience in trying to get a diagnosis is not unusual. Dr. Rivello does not believe it is a new condition. “I think it's something that's always been there ... I've

Gerbers/13

any genetic strands ... It is just a fluke."

Through trial and error, however, they have discovered that strong fragrances — perfume — and excitement trigger attacks in Sean.

It was seeing all those people at the conference that prompted the Gerbers to start thinking about the need to do something to raise awareness and money for research.

The idea for the May 5 event was born.

Life goes on

Sean still takes a bottle because he can't hold a cup.

When they take the children to the mall, people stare or make comments about him being a bit old to have a bottle.

She has to feed him, especially if the food requires a spoon. His speech is poor "however, his receptive skills are right on target." When asked if he wanted a pudding, for instance, he went right to the refrigerator.

Sean started to walk when he was 30 months old. "Most of the kids don't ever walk," Mr. Gerber said.

Since the end of February, Sean has been what they call "in episode" more than he has been out. "They seem to be coming more often," Mrs. Gerber said.

The paralysis can last from a couple of minutes up

to two weeks.

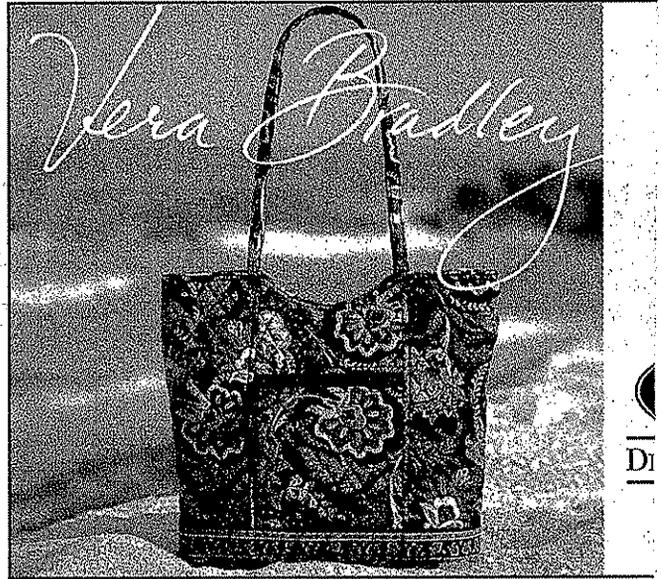
It is a degenerative condition.

"Sean being born with it, they expect the worst ... he will be severely retarded."

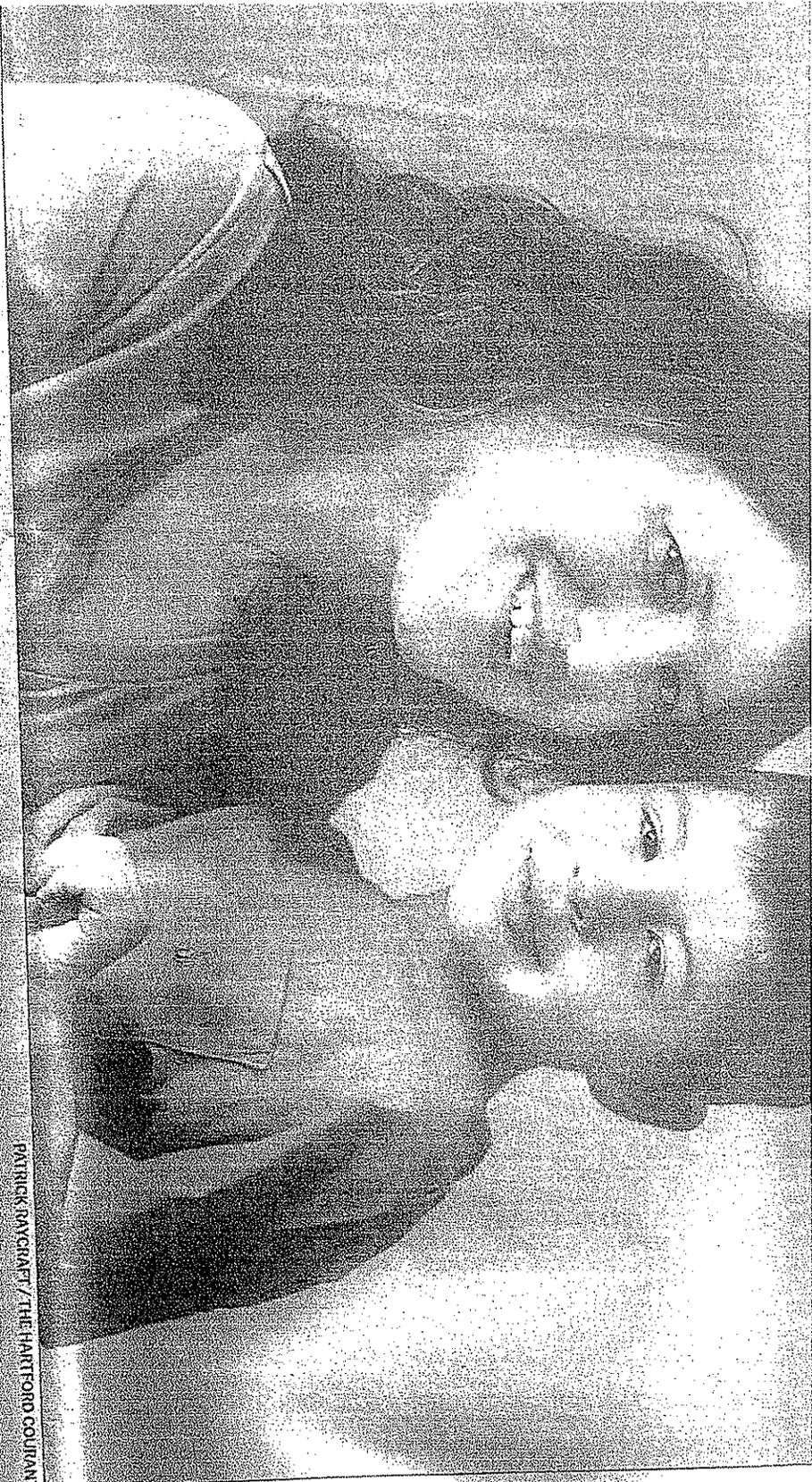
Mrs. Gerber hopes a cure will be found.

"No family should have to go through what we have gone through." **SWL**

For more information about the auction and dinner dance, call 680-9410.



Another dental visit?



PATRICK RAVENHART/THE HARTFORD COURANT

OLGA GERBER holds son Sean, 4, who has Alternating Hemiplegia of Childhood, a degenerative disorder.

Raising Awareness Of A Rare Disorder

By RUTHIE ACKERMAN
COURANT STAFF WRITER

SOUTH WINDSOR — By all appearances Bill and Olga Gerber and their two children live a normal life — toys scattered on the living room floor, family pho-

SOUTH WINDSOR

tos adorning the fridge, two cars in the driveway. Despite the veneer of normalcy they struggle to raise their 4-year-old son, Sean, who has a rare degenerative disorder with no cure. Sean has Alternating Hemiplegia of Childhood,

which causes transient neurological attacks paralyzing anywhere from a portion to all of his body. In the best case scenario Sean has a mild attack that causes his eyes to roll from side to side. At worst, Sean goes into full body paralysis leaving him unable to even lift his head. An episode can last anywhere from several minutes to two weeks and the Gerbers never know when the next one will strike.

"If Sean was the same way every day we could deal with it. The roller coaster — good one day, not the next — is hard. You can't plan. You have to just start doing," Bill Gerber said.

The couple also has a 7-month-old daughter, Shelby, who has shown no symptoms, although they could occur anytime in the first four years of life.

"Sometimes, she'll be crawling at noon and it will break me out," Olga Gerber said.

Most families have plans for where they see themselves in the future. Retirement and living in a colonial were two of the Gerbers' goals. But with Sean's disorder, even going out to dinner has become an impossibility.

"Other people can get baby sitters. If we have to go out we just can't," Olga said.

"If God forbid, something happens we have to be here," Bill added.

To raise awareness about the disorder and to help find a cure, the Gerbers are holding a fundraiser for

PLEASE SEE PAGE 34

Promote Safety

Business owners and officials have a responsibility to protect meetings and employees from the threat of safe falling and

BY THOMAS J. ...
... ..

Every time ...
... ..

ARE AWIDE

The gate ...
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There's not one ...
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A House bill that proposes ...
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ATV owners now are supp ...
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Sean

CONTINUED FROM PAGE E3

the Alternating Hemiplegia of Childhood Foundation, AHCF, today from 6:30 to 11:30 p.m. at Maneeley's Banquet Facility on Rye Street. The \$40 ticket price will include dinner, a silent auction and a dance, and all proceeds will go to AHCF.

According to Lynn Egan, vice president and family support coordinator for AHCF, there are 350 people in the world, four of them in Connecticut, who have been diagnosed with the disorder. Egan believes there are others who either have not been diagnosed or have been misdiagnosed. Some with AHC have no symptoms and live normal lives except for the occasional episode. Others are in wheelchairs and cannot move without assistance.

"It's not a cut and dry disorder. Every child exhibits the same type of symptoms, but the range of ability is very different," said Egan.

In his navy blue sweater and

blue cargo pants, Sean seems happy. Yet at 4, he still wears diapers, drinks from a bottle and can barely walk on his own.

Even though Sean is developmentally delayed, he is cognitively aware of his situation, and he is learning to work around it. At times he expresses himself using sign language and, during his worst attacks, when he goes into full body paralysis, he communicates with his eyes.

AHC is a degenerative disorder, which means the forecast is grim. One of the families the Gerbers met at the annual family reunion the foundation holds had a daughter who lost all mental and physical abilities after an attack.

"When Sean's in these episodes I always wonder if this will be the one to wipe him out," his mother said.

For more information about AHC visit the website www.ahc-kids.org. For fundraiser ticket information call 860-680-9410. Contributions may be mailed to Olga Gerber, 173 Windsorville Road, South Windsor, CT 06074.

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