SERTOMANS WORK TO UNLO

Your child has autism.

In the United States, that life-altering diagnosis is delivered to a child's family every 22 minutes according to data published by the Fighting Autism Project. It signals the beginning of a journey in which the smallest of accomplishments are cause for joyous celebration. It leads families down a long, grueling and expensive path of biomedical treatments and therapies. And it triggers frustration and anguish in parents who wonder how or why this could have happened.

Meet Renessa, Darrell and their son Lawson. Born in the Marshall Islands, Lawson was adopted by Renessa and Darrell at four months of age. "When we arrived in the Marshall Islands and I set eyes on Lawson, I instantly knew this was my son; he was the most beautiful baby I had ever seen," said Renessa. But joy quickly turned to concern caused by a persistent rattling sound in baby Lawson's chest. Renessa had little confidence in the medical care Lawson was receiving and knew that a check-up by her own doctor would be the first order of business once the family was back home in Louisiana. That check-up came sooner than expected when Lawson was rushed to the hospital emergency room the very day they arrived back home. And over the next 18 months, baby Lawson and his family spent many long days at the hospital as doctors fought chronic pneumonia, fluid build-up in his lungs and persistent digestive problems.

At first, Renessa wasn't particularly troubled by Lawson's lack of speech, chalking it up to his many physical problems. "This was my first child and I really wasn't sure what to expect," she said. But when Lawson still wasn't talking at age two, Renessa shared her concern with her pediatrician. He dismissed it as a case of some children developing speech and language skills slower than others. Then Lawson stopped responding when his parents called his name. "I knew Lawson knew his name and thought maybe there was a problem with his hearing," said Renessa. A battery of hearing tests showed no hearing deficits and soon thereafter, Renessa and Darrell heard those life-altering words, "Lawson has autism".

A report on the local TV news sent the family to Baton Rouge to meet with Dr. Stephanie Cave, a physician with the DAN! (Destroy Autism Now!) Project, who was using a combination of biomedical treatments to successfully treat children with autism. Beginning with that first visit to Dr. Cave, Lawson and his parents embarked on a long road of treatments and therapies that included hyperbaric treatments, IV chelation, auditory training, speech therapy, sensory integration therapy, light therapy, applied behavior analysis, numerous natural supplements taken daily and a gluten-free, casein-free diet to correct what Renessa refers to as "leaky gut syndrome". Renessa says she can't point to any single one of the treatments or therapies as the one that made a difference but says the combination began to create positive changes in Lawson.

Today, Lawson is eight years old and attends school where he participates in a mainstream first grade classroom. He has some verbal communication abilities, reads, writes and takes written tests administered one-on-

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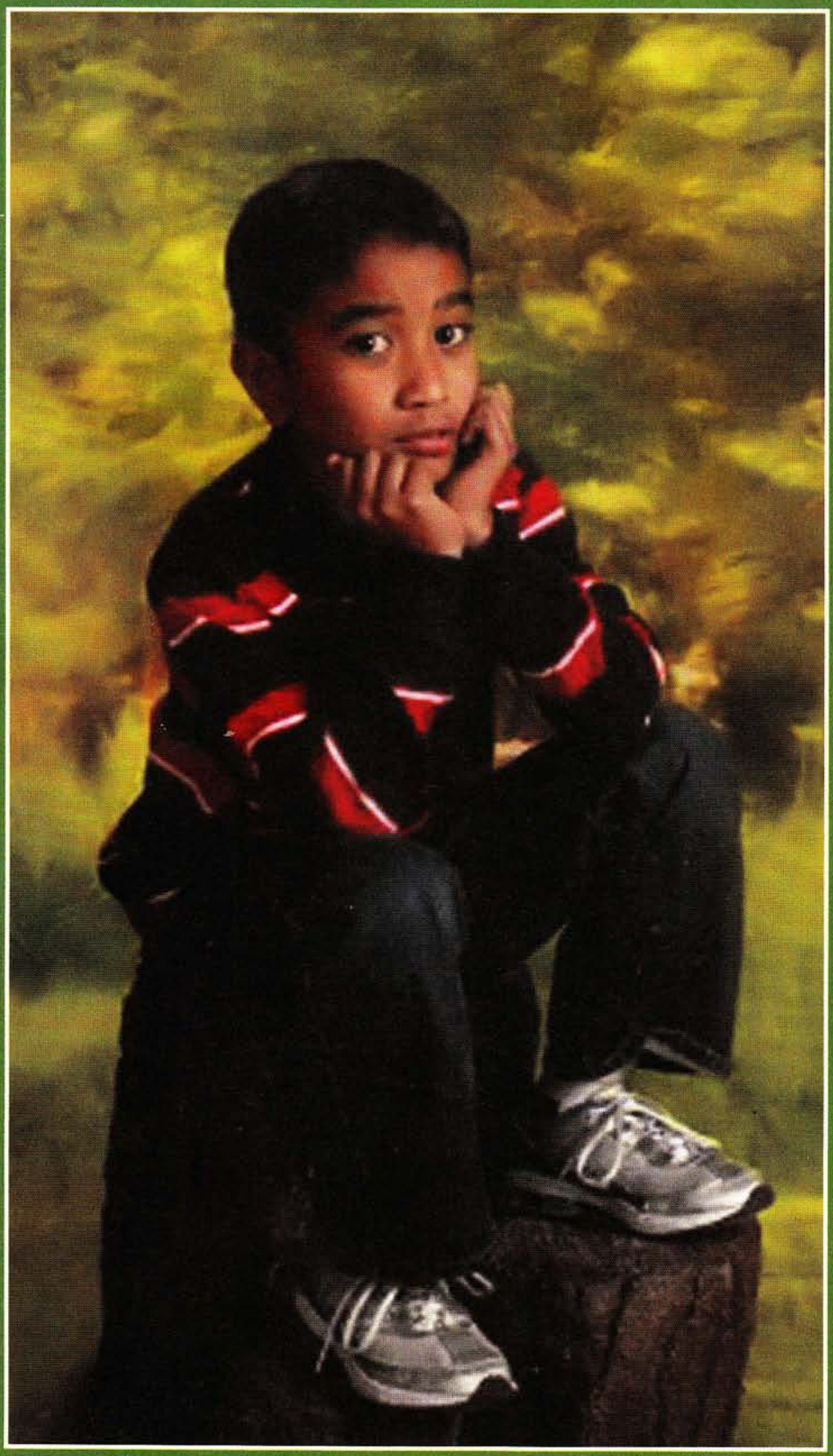

one by his teacher. "People who don't understand autism sometimes think the child is mentally retarded or violent," said Renessa. "Lawson is a very loving and smart little boy who can learn the same as other children; he just has to learn in different ways with lots of repetition." Lawson recently learned his parents' names, a breakthrough that generated great excitement for Renessa and Darrell. "Every little thing he does is a milestone for us."

According to Dr. John W. Oller, Jr., Hawthorne Regents Professor, Department of Communicative Disorders, University of Louisiana, Lawson's story is fairly typical of those told by a growing number of parents whose children are diagnosed with Autism Spectrum Disorder. In fact, he says the number children diagnosed as autistic is not simply growing, "it is already at epidemic proportions". According to data collected by the US Department of Education and other government agencies over a 13 year period measured from 1993 to 2006, the number of reported diagnosed cases of Autism Spectrum Disorder increased 1,342%.

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Autism currently affects an estimated 1.5 million children and adults and is cited by the Centers for Disease Control as the fastest growing childhood disorder in the United States. With reported diagnoses projected to increase at a rate of 10-17% each year, the number of children and adults affected by autism could reach four million by the next decade.

As awareness of autism grows, research to identify its causes and development of new biomedical treatments and therapies are giving hope to families of autistic children. And the Sertoma Club of Lafayette, Louisiana is playing a key role in helping to advance understanding of this mysterious – and growing – disorder.

In 2004, the Sertoma Club of Lafayette was looking for a worthy cause to support with proceeds from the Club's highly successful Sertoma Cajun Air Festival. Dr. Oller, who had returned actively to the club in 2003 after a three year sabbatical, suggested sponsoring an international conference - held in Lafayette - that would focus on the causes and treatment of autism. This would be a first in the region and the Lafayette Sertomans agreed it was a very worthwhile use of the air show funds. The club donated $30,000 to help underwrite costs of the conference and additional funds were donated by the University of Louisiana, the Tourism Bureau of Lafayette and various private sponsors. The Autism Society of Acadiana stepped in to provide assistance and Dr. Oller quickly went to work to organize the conference, soliciting participation by world-renowned experts in medicine, toxicology, biosciences, and psychology. The conference was accredited for continuing education in medicine, dentistry, nursing, speech/language pathology, occupational and physical therapy.

In April 2007, more than 200 specialists, including parents of children with autism, gathered in the Cajundome in Lafayette for the SERTOMA International Conference on Autism Spectrum Disorders. Over three days, they learned about the latest research on potential causes of autism and promising treatment protocols such as Applied Behavior Analysis. In that same year, the Sertoma Club of Lafayette adopted the Autism Society of Acadiana as its first official affiliate.

Energized by the information that came out of the conference, the Sertoma Club of Lafayette sponsored an Applied Behavior Analysis seminar just a few months later. And in 2008, the club bolstered a $3,000 matching grant from the Sertoma Foundation with its own $12,000 grant to support study of the biomedical side of Autism Spectrum Disorder.

The conference and the network of collaborations developed with support from Sertoma and the Sertoma Club of Lafayette resulted in publication of a three-book series, co-authored by Dr. Oller. The first book appeared in 2006 and two books were published last year. The series examines communication across the life span, beginning with normal speech and language development, then dealing with communication disorders, and culminating in the study of Autism Spectrum Disorder, its diagnosis, causes

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and treatments. Royalties from that book are going to help fund treatments for autistic children in Lafayette.

Autism Spectrum Disorders, often referred to simply as "autism", consist of behaviorally defined neurological problems affecting brain development. It typically appears in children by the age of three and is four times more likely to affect boys over girls. According to Dr. Oller, it is possible to distinguish 16 different levels of severity along the Autism Spectrum and symptoms can vary greatly from one child to another.

The connection between autism and speech/language is, in Dr. Oller's words, "fundamental because diagnosis depends on noticing abnormalities with a child's language and speech". Sometimes the abnormality appears as a delay in a child's speech and language development. In other cases, children whose communications skills were developing normally suddenly regress, losing the words they had already learned. "One of the first things parents commonly notice is that the child stops responding to his or her name, as was the case with Lawson," said Dr. Oller.

Non-verbal communication is also affected by autism which makes it difficult for the child to understand and interpret non-verbal cues like body language, tone of voice, facial expressions or gestures. A variety of behavioral characteristics are used to diagnose autism. These can include rigid resistance to changes in routine, repetitive behaviors such as hand flapping or echolalia (repeating the same word or phrase over and over), withdrawal, insensitivity to pain and no apparent fear of real danger, hypersensitivity in one of the five senses, difficulty making or keeping eye contact, shrieking or violent outbursts. Dr. Oller suggests that shrieking and sometimes self-injurious behaviors are known in some cases to reflect the child's reaction to pain caused by gastrointestinal problems that are also prevalent among autistic children. Chronic convulsions affect about one-third of individuals with the diagnosis and twice that proportion have abnormal epileptiform episodes short of full seizures.

Although there is not yet a recognized cure for autism, Dr. Oller says that advances in biomedical treatments are generating "documented cases of remarkable recovery". And ongoing research may one day provide definitive answers on causation. "We already know that toxins, certain disease agents and their interactions are involved."

In the meantime, Lawson's mom and dad continue to fight tirelessly for every small breakthrough, cherishing each one when it comes. Lawson recently became a big brother when Renessa and Darrell adopted their second child, a five-month old son named Landry. Renessa hopes that as the boys grow up together, Landry will inspire and lead Lawson to more and more breakthroughs. For his own part, Lawson has been a source of inspiration to his family, including stepsister Melissa who is pursuing a speech pathology degree at the University of Louisiana in the hope of one day helping other children like Lawson experience their own breakthroughs.