

February 2007

# Sonnenberg Consultants Newsletter

"Yipee Ocean!" (trying to say woopee cushion) (Matthew-Age 4)

## Research Updates

GoodSearch is a Yahoo! powered search engine that donates 50% of its revenue to the charities its users designate. Each time you search using GoodSearch.com, the site donates a penny to a nonprofit, charity or school of your choice. Use the following link to visit GoodSearch.com and support Autism Speaks.

Chicago White Sox Autism Awareness Day

### **Benefiting:**

[Athletes Against Autism](#)

[Cure Autism Now](#)

Sunday, April 29, 2007

1:05 PM @ U.S. Cellular Field

[Chicago White Sox](#) vs. [Los Angeles Angels of Anaheim](#)

(323) 549-0500, ext. 747 or [slevitt@cureautismnow.org](mailto:slevitt@cureautismnow.org)

The National Autism Association (NAA) announced today the receipt of two grants for the Burbacher/Charleston study into the effects of mercury exposure in the brain. The Doug Flutie, Jr. Foundation for Autism, Inc. awarded a \$20,000 grant, along with 25 other grants to organizations totaling over \$357,000. Speedway Children's Charities (SCC) of Concord, NC, will also support the research with a \$10,000 grant from its national charitable funding program. SCC awarded more than \$2.8 million to over 470 organizations in 2006.

U.S. Autism Population Estimate  
01/21/2007 05:20 PM PST  
( ages 3-22 )  
231,129

U.S. Annual Economic Cost  
\$6,933,892,482

Next Diagnosis  
5:47 mins

[www.FightingAutism.org](http://www.FightingAutism.org)

## **An Evening with the Stars February 25, 2007**

Walk the red carpet for Autism Awareness, at NBC Studios in Chicago.

This Oscar-themed celebration features an elegant pre-show dinner at Catch 35 Restaurant, a Trolley ride through the streets of Chicago, and a stroll down the red carpet at Studio A inside NBC Tower. The evening culminates with the live viewing of the 79th Annual Academy Awards telecast on the big screen inside Studio A at NBC Tower. The evening also features a fantastic silent auction and raffle including vacation packages, movie themed paraphernalia, and much more. Don't miss the best party in Chicago on Oscar night. For more information, go to [www.eveningwiththestars.org](http://www.eveningwiththestars.org)

Congress to include \$7.5 million specifically for autism research in the FY [2007 Defense Appropriations bill](#). These funds can be used for biomedical and other research aimed at finding the cause(s) and effective treatments for autism for the benefit of affected military families and the community at large.

## **Autism Speaks and Cure Autism Now Complete Merger**

**Combined Operations of Leading Autism Organizations Will Lead to Enhanced Research, Treatment and Advocacy Programs**

Autism Speaks and Cure Autism Now (CAN) have completed their merger, uniting the nation's two leading autism advocacy organizations and their cutting-edge programs for research, treatment, and family services. Mark Roithmayr, president of Autism Speaks, announced today that the Boards of Directors of Autism Speaks and Cure Autism Now respectively had approved the transaction. The groups first reported their intention to merge in November 2006. The combined entity will be known as Autism Speaks.

## Classifieds

-Help in a Racine household to be present while therapy is going on downstairs and to feed and play with the child between sessions. If interested please contact Shelly at 262-634-8187.

MVP of this month is...

### MeLinda Floore

**Thanks so much for helping out with all the file folders and stimuli! MeLinda donates her time to help us with stimuli for all the families even though she has a ABA program herself. Thanks MeLinda!!!!!!!!!!**

## Media Updates

Some of Hollywood's biggest stars, including Golden Globe winner Alec Baldwin, showed their support for Autism Speaks and its mission of autism awareness and research by wearing the organization's distinctive blue puzzle piece lapel pin on their tuxedos and gowns during the Golden Globes ceremony last week.

Regal Theater Group will show Autism Speaks' public service ads before every film on over 6,300 screens April 6-12, Autism Speaks and Regal announced. The spots, produced by the Ad Council, will be shown as part of Autism Awareness Month.

Autism Every Day was featured in a special hour-long exploration of autism on the popular daytime program "The View." The show, aired on Monday, Jan. 29 at 11:00 a.m. ET on ABC, included was interviews with medical experts, individuals with autism and their families. If anyone missed this program than ask Farrah for a copy.

## Company Policies

-Parent input is also welcome in nominating the MVP of each month. Just let your Senior or Farrah know.

-Our website will be posted at the end of this month. The site is [SonnenbergConsultants.com](http://SonnenbergConsultants.com).

-If any tutor has not taken their line test please let your senior know.

## Joke of the Month

Confucius say. . . .

He who run behind a bus get exhausted.

### **Bonus laugh:**

Ever stop to think, and forget to start again?

## Happy Birthdays to...

Marie Johnson-29 years old!

Lindsay Hofmann-24 years old!

Nichole Ragla-25 years old!

## Projects to help with...

-Help us make a name for our company! We are going to add a phrase that will follow Sonnenberg Consultants and if you win then you will receive a prize. Be creative and have fun! Ask your senior for details.

## Materials/Stimuli information:

DreamCatcher tm Blankets, with a patent pending design, specializes in making custom weighted blankets for those who are comforted and benefited by them. Being specialized and focused on offering only weighted blankets and lap pads, provides our clients with a superior product. We make larger blankets ( up to king size) for sleep, in addition to wrap and lap blankets , and lap pads which are smaller and used mainly as a calming tool. People who have benefited from DreamCatcher tm Weighted Blankets include children, teens and adults affected by Autism Spectrum Disorder, ADHD, ADD, PDD-NOS, Sensory Integration Disorder or have other sensory issues.

DreamCatcher tm weighted blankets

have also been used with people suffering from Alzheimer's, Restless Leg Syndrome, and Insomnia with good results. In addition, we have several customers who have purchased sleep blankets who just have trouble sleeping and have found the blankets to be an extremely helpful, natural drug free sleep aid.

<http://www.weightedblanket.net/>

## Articles:

Is Autism an Epidemic?

### **Anthropologist Argues No!**

How did autism shift from being a rare disorder, occurring in 3 in 10,000 people, to an "epidemic," occurring in 1 in 166 people? A controversial new book by anthropologist Roy Richard Grinker claims it didn't.

"An increase in prevalence," Grinker says, "is different from an epidemic." He notes that the current rate of 1 in 166 is the best and most accurate rate we've ever had but is not necessarily evidence of an epidemic.

In *Unstrange Minds: Remapping the World of Autism*, Grinker undertakes a global study of autism beginning with the personal story of his autistic daughter Isabel and his family's battles with the school system. Grinker uses his research on autism in the United States and abroad to argue that there is no evidence for an autism epidemic, at least epidemic as it is traditionally defined by the medical community. Instead, he writes, the high rates of diagnosis today are evidence that scientists are finally, after all these years, counting cases correctly.

Many parents of children with autism say they disagree with Grinker's theory.



Daniel completing a file folder

### **Finding the "Beautiful" in Autism**

#### **Father Writes of his Autistic Daughter's Successes**

Sometimes, at night, Isabel has a hard time falling asleep. It helps her if I sit in a chair in her bedroom. Looking at her then, from across the room, I see two different Isabels. There is Isabel awake—often hyperactive and isolated—and Isabel asleep, a beautiful child drifting into a calm night. And then I realize something unsettling: I feel more affection for the sleeping Isabel. She looks so peaceful and relaxed. And I wonder what this says about me. Do I love her less when she's a real person, awake and in the world?

When I can hear each breath, I know she's finally fallen asleep, but I sit for a minute more—just to make sure, I tell myself. The truth is, it's nice to be in the same room with her without having to work so hard.

Isabel has always been a slim girl, but she has a round face that invites kisses. Joyce calls her cheeks "bo-bo-bos," some Korean baby talk she learned as a child that refers to balls of fat in adorably plump babies. Before I leave her room, I kiss her cheek, and she's usually sweating, as children so often do in their sleep. I think about how much she has to struggle every day, just to deal with what to her must be chaos, and what to most of us is simply everyday life.

I try not to think about what other teenage girls are like—the ones I see outside our local middle school, gossiping and talking about boys—and focus only on Isabel. If I compare her to the rest of the world, she seems so impaired. But if I compare her with herself, and consider all the progress she's made, more than any doctor ever predicted, I'm suddenly filled with respect for her. I don't know how she keeps herself so happy.

It's at those moments I have an odd feeling of liberation. I remember that during my childhood one of my cousins described having a child with a severe disability as "a prison sentence." It doesn't seem that way to me because I cherish the idea of being with Isabel forever. Joyce and I are free of the stressful ambition of having Isabel go to a high-status high school or college, free of the anxiety about a child

leaving us to live somewhere else or marry.

I am not a religious person, but there is something profoundly meaningful, if not spiritual, about being the father of a child with autism that has pushed me to consider lofty, abstract principles of life like truth, beauty, and goodness. I just have a hard time seeing them during the day when I'm fighting with Isabel to stay near me on a sidewalk next to a busy street, pay attention to her homework, or turn off the television.

Now she's asleep for the night, her plush Panda bear under her right arm. When she wakes up, the everyday struggle will begin all over again.

It's the struggle of getting her to communicate, to learn, to say yes or no to a simple question, to come to the dinner table and sit with her younger sister, Olivia, to eat foods other than hot dogs and pizza, to stop putting her hands over her ears in response to some sound or frequency no one else can detect.

Especially in the early years, I'd lose my temper when I was frustrated by her inability to communicate. Joyce would lose her temper too. Our younger daughter, Olivia, would start to cry if we raised our voices. There are moments of intense emotion in any family, and most people regret them. But when you're facing something like autism, whether your child is severely affected or not, you've got to cut yourself some slack. I used to justify my expressions of anger and frustration by insisting that Isabel needed to be exposed to the full range of human emotions. The problem was that Isabel has usually responded to anger and loud voices and ignored gentle, quiet ones. I'd start out quietly, asking, "Do you have to go to the bathroom? Yes or no?" But she'd only notice me when my voice got loud. "Answer me!" The more I expressed my frustrations, however, the guiltier I felt, especially at night when I looked at her sleeping, so beautifully. How could I have been so mad at such an angel?

And if you knew how far she's come, you'd probably ask me the same question.

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Joyce and I were married in the summer of 1990. I had finished my Ph.D. in anthropology at Harvard University, having spent two years living with the Pygmies in what was then called Zaire, now the Democratic Republic of Congo. I was studying ethnic conflict and nationalism, nothing at all to do with mental disorders or autism. Joyce was a newly minted psychiatrist doing a fellowship at Harvard Medical School in medical anthropology, the branch of my profession that studies how culture affects the way we experience and treat illness.

Our first child, Isabel, was born in September 1991 in Minneapolis, where we had taken our first jobs. Isabel was extraordinarily beautiful, with an enigmatic face, a mixture of Korean and Caucasian features. She

would have Joyce's lovely black hair, my pale skin, and eyes a gray-blue color we thought genetically impossible, eyes framed by eyelashes so long they looked unreal. We never had a clue that anything was wrong until 1993, a year after we moved to Washington, D.C., and Joyce gave birth to our second daughter, Olivia.

Isabel was two, and she couldn't talk.

\* \* \*

When I think about the day Isabel was diagnosed with autism—as if that was the first day she really had autism—I'm reminded of how memories privilege events over process. We think of our marriages, for example, as a first date, an engagement, the wedding; we punctuate our children's lives with birthdays, or the first day of school. But the reality of our social lives is a gradual march of time, a complicated process of building relationships.

I trace the beginning of my knowledge about autism, and Isabel's identity, to a single event, a beautiful spring day in 1994, when a short, slightly overweight, affable child psychiatrist told us, "Isabel has enough features of autism to be called PDD-NOS, Pervasive Developmental Disorder Not Otherwise Specified. It means that she's not severely autistic." But, in fact, by that time we had already been worried about Isabel for more than six months and we were sure there was something different about her. The diagnosis was really just about someone we could trust telling us what we knew all along, even if we didn't admit it to ourselves.

Despite the joy of our second daughter's birth in November 1993, the year 1994 would begin poorly. In her first two years, Isabel had seemed to us like any other child, and at twelve months she had begun to make some of the sounds that seemed like the beginnings of words. But she was our first child, and so we didn't really have a standard for comparison. We thought she was fine. But when I look at our home movies today, I see that she never once tried to communicate with us; in none of the videos of Isabel between eighteen and twenty-four months does she say a single word.

She may not have tried to communicate with words or gestures, but she did interact with us, and she looked so normal. There's a pretty, happy, dark-haired little girl hugging and kissing us, playing hide-and-seek and ring-around-the-rosy in the living room of the house we rented in Chevy Chase, Maryland. I play an electric piano as she dances on her toes. Joyce tickles her, one hand on the camera, one hand on Isabel's belly, and they both squeal. Had there been someone else in the room watching, he would have thought to himself, "Now there's a happy family."

She used to carry Mickey and Minnie Mouse dolls with her everywhere. In one film, Isabel throws Mickey and Minnie on the floor outside of our

bedroom, then goes inside and shuts the door. A few seconds later, she peeks outside the door to see if they are still there. Our new baby, Olivia, sleeps in her crib as Isabel meticulously arranges the dolls on either side of her and tucks her, Mickey, and Minnie into bed, as if they were three dolls.

It had been just the three of us, until now. Three, a unity so perfect that it blinds you. Only now, with Olivia here, an outsider in the way that all second, third, and fourth children are outsiders, did we start to look at Isabel with a worried eye. Olivia made us see Isabel anew, if only because we tried to assess how far we and Isabel had come, what kind of parents—and what kind of sister—Olivia was about to meet. And what we saw gave us pause, like when relatives come late to a dinner already in progress, and you stop what you're doing, take stock, and feel somewhat sorry for having begun without them. You make way, starting over. We looked at Isabel as if for the first time, and we began to see how different she was from other children her age. It was a bit like we had two new children.

A few months before Isabel's second birthday, and Olivia's birth, Isabel appeared to be losing what little language she had. That winter, in December 1993, while Joyce and I were focused on things other than Isabel—making dinner, changing Olivia's diaper, cleaning the house—our ears would occasionally perk up when we thought we heard Isabel say a word or two. We called these events “Elvis sightings” because, even though we were never certain she'd actually said something, we were still excited. We may have just believed what we wanted to believe. But she had crawled and walked on schedule, was almost completely toilet trained, and apart from the speech problem, didn't seem unusual. We didn't notice that she made little eye contact.

Our new pediatrician in D.C. had been reassuring. He was a bland, if brusque man who insisted that Isabel was “normal” and that there was nothing to worry about. He blamed the speech delay on the fact that Joyce and I spoke some Korean to Isabel at home—Joyce is Korean American and I have studied Korean—and had a Korean babysitter who spoke little English.

“Normal.” It's the word every parent wants to hear. Pediatricians are so well trained to use it that I've wondered if they get bored with it. I realize that in most cases they are right, that new parents often need reassurance, and that speech delays do sometimes occur in bilingual households. But there is that cynical side of me that imagines new pediatricians attending a training center someplace where they learn how to look sweet, dress in Disney ties, bow ties, or scarves to look just a little ridiculous, and say things like “He'll be fine ” so the hysterical mom will just go home.

It turns out that my cynical side is not that far off the mark. Years later, after interviewing dozens of families with autistic children in several countries, I repeatedly heard different versions of the same story—in India, South Africa, Korea, and in telephone conversations with parents in Trinidad, Croatia, Peru, Kenya, Namibia, and Venezuela. Typically, the mother is the one who brings the child to the pediatrician. He dismisses her concerns and makes her feel that she is overanxious, if not hysterical. If it is a boy, he says that boys always speak late; if it is a girl, he says she's just a polite child. Pediatricians are trained to be reassuring. But the directors of parent-run advocacy organizations will tell you that the number-one target for all their efforts in promoting autism awareness is the pediatrician.

And they are right to do so. Some pediatricians still think of autism as fairly uncommon, and they have been taught not to go searching for uncommon disorders—as the medical school saying goes, when you hear hoofbeats, look for horses, not zebras. Yet we know that the earlier autism is “picked up,” the better the potential outcome. Many pediatricians want to wait until things are really bad before giving a diagnosis—until, as one doctor told me, “the delay is bad enough that the kid cannot do what is expected of him.” The problem is that little is expected of one- and two-year-olds, when the symptoms of autism sometimes appear, an age where pediatricians can dismiss parents' concerns because children develop at different rates.

To be fair, I also think that pediatricians are getting a bit of a raw deal. The pediatrician may say something like, “He's probably just fine. We can't know yet if anything is wrong; for now, give your child a stimulating environment—take him to baseball games, go on a camping trip, do fun things together, and let's see how he's developing in six months.” The parents later retell the story with the bitterness of someone who has been called a liar or hysteric: “Our pediatrician told us we should just go to a baseball game.”

Joyce did not like our first pediatrician, finding him too paternalistic. I thought the new doctor was too anxious, but Joyce had been given her name by physician colleagues, so she felt comfortable with her. “We need to know if something is wrong with Isabel,” Joyce said. “We need to pursue it.” The first exam proved that Isabel did not have a hearing problem (one of the first things you rule out when assessing a language delay), but the developmental checkup was inconclusive. She told us to come back in a few months. We were satisfied that she took our concerns seriously, but she certainly never used any diagnostic terms. Joyce and I never talked about autism. It wasn't in the air; I didn't know anyone with autism.

We had an infant, a child with a mysterious developmental problem, and on top of it I was getting

ready to come up for tenure, the make-or-break time in a professor's career, when you find out if you'll be given total, life-time job security or be fired. Joyce was working long and difficult hours as the director of the psychiatric in-patient unit at Georgetown. The stress was unbearable at times, and it took a toll on our marriage and on our relationships with our respective parents and parents-in-law.

Isabel, now twenty-five months old, made only fleeting eye contact. She began flapping her hands and arms occasionally and didn't respond to her name consistently. We were at a point where we demanded clarity and accuracy from doctors. A valid diagnosis of what was wrong with Isabel would be more satisfying than devastating. But neither of us thought any doctor would again tell us that Isabel was normal.

By this point, the time for Isabel's follow-up visit with the pediatrician had arrived. She noted the same symptoms we had seen but focused more on Isabel's speech. Her ability to talk, even to make sounds, had diminished since the last visit. The doctor paged Joyce at work the next day: "I've been thinking about my exam with Isabel and I'd really like you to see a child psychiatrist who specializes in autism." Joyce knew little about autism. In her entire psychiatric residency at Harvard's Massachusetts General Hospital, arguably the best residency in the United States, she had never once seen a case of autism.

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The pediatrician recommended we see a speech pathologist at Washington Children's Hospital as well as a child psychiatrist. The speech pathologist determined that at the age of thirty-two months Isabel could say about 70 words, which might not sound so bad for a two-and-a-half-year-old, except that a typical child knows about 100 words by the age of two, about 500 by the age of three, and well over 1,000 by the age of four. More importantly, a typical two-year-old also uses what few words he or she knows to interact with others. Of Isabel's 70 words, all were nouns. A third were the names of "Thomas the Tank Engine" trains, a third the names of Disney characters, and the rest numbers and Korean nouns she learned from Joyce or our Korean babysitter.

The list didn't include "mommy" and "daddy." Isabel was unable to create sentences or even issue commands. She couldn't tell us if she was hungry or thirsty. She couldn't even say "yes" and "no." And except for pulling Joyce or me to the refrigerator when she was hungry, she didn't use gestures to communicate. Five months later, she had yet to learn a single new word. On the plus side, her articulation was great, so if she did learn language she would likely have no speech impediment, and the speech pathologist noted that Isabel seemed to be good at doing simple puzzles. Her visual and spatial memory looked strong, and this, we were told, was a sign of good intelligence.

The first child psychiatrist we saw was a disaster for us because he blamed Joyce for Isabel's autism. Joyce left his office angry, and I left feeling like I must be a horrible father. So we moved on to a child psychiatrist in Baltimore. We were lucky to be able to get these appointments, since there is a shortage of child psychiatrists in the United States.

By the time of the first meeting with our new psychiatrist, we had looked at a few books on autism and we had a strong suspicion of what was wrong with Isabel. In Baltimore, the psychiatrist sat calmly with Isabel on the floor, dolls and toys scattered around him. Isabel picked up a small, plastic brush for combing a doll's hair and started to brush the doctor's hair. Never the distant doctor observing the child like a scientist, he was engaged and comfortable with Isabel while she brushed him. He had in his office a DSM-III-R ( Diagnostic and Statistical Manual, Third Edition, Revised ), the current diagnostic manual at that time. He showed us the criteria for autism and related disorders, all classified under the heading of "PDD," and then drew our attention to PDD-NOS, Isabel's diagnosis. But it seemed to me that Isabel did fit the criteria for autism. She couldn't make friends or communicate with words or gestures. She used repetitive speech and was preoccupied with lining things up in a row. So why didn't he say she was autistic?

He explained that while it was true that Isabel had most of the features of autism, she had them to a lesser degree than many of the other children he had seen in his years of practice as a child psychiatrist, and she showed no evidence of being mentally retarded (though the absence of mental retardation never rules out an autism diagnosis). In retrospect, I think he may have been afraid to give us a devastating diagnosis like autism when Isabel was so young and in some ways functioning at a higher level than other children he had seen. As a child psychiatrist from Fairfield County, Connecticut, told me recently: "Things are different now. Even in the mid-90s, autism used to be like the 'c' word [cancer], and I didn't use it if I didn't have to. So it was only the severe cases that got an autism diagnosis from me. The others got 'PDD-NOS.'"

In fact, I remember that, despite knowing little about autism, I felt happy that Isabel had PDD-NOS instead of autism. I didn't realize then that, over time, PDD-NOS would prove to be an ambiguous and cumbersome diagnosis, that it would morph into "autism" or "autism spectrum disorder," and that I'd rarely use the term PDD again. Today, Isabel is simply a child with "autism."

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Isabel was enrolled in a small preschool in Chevy Chase, Maryland. Our psychiatrist recommended that we keep her there so that she could be with "unimpaired" children, children who might serve as

good social models. The topic of arranging one-on-one, intensive, in-home therapies came up only briefly. Then Joyce heard about the kind of preschool you just don't turn down, a hands-on, museum-based preschool at the Smithsonian Institution.

I remember well the mornings I brought Isabel to the Smithsonian. She used to linger outside the National Museum of American History, where her classroom was located, exploring the trees and gardens. Watching her there I realized for the first time that she had heightened visual skills. She looked around constantly, memorizing everything.

On winter mornings, you could see the glow of sunrise above the Capitol building, sometimes turning the Washington Monument a light shade of orange or yellow or even purple, a color so pale you weren't sure what it was. There are twenty-foot Saucer Magnolias around many of the museums, lindens and hollies, ginkoes and weeping birches, whose shapes and textures made Isabel stop and stare, not so she could avoid going to school, but, it seemed to me, to fix in her mind memories of the place she now spent all her days. I recall most vividly the occasional patches of *Corylus avellana* "Contorta," one of the strangest looking trees you'll ever see. The *Corylus* branches, revealed in winter, twist and curl as if afflicted with a mysterious disease. It doesn't grow like a tree is supposed to.

Every day at the Smithsonian Early Enrichment Center the children went to at least one of the more than eighteen museums at the Smithsonian, or to nearby museums, such as the National Gallery of Art, extending across the Washington Mall. If they were supposed to learn about shapes, they went to the Hirshhorn Museum and Sculpture Garden, the Smithsonian's museum of contemporary art, to find shapes in paintings or sculptures; if they were supposed to learn about insects, they went to the entomology department at the National Museum of Natural History. When they needed to learn about emotions—one of Isabel's most difficult tasks, largely because she didn't like to look at faces—they went to the National Portrait Gallery on a hunt for as many emotions as they could find. The Smithsonian was an ideal place for a child with strong visual and spatial skills, like Isabel, but few verbal skills. She had the opportunity to move around a lot, and she could be with unimpaired kids who modeled social behavior for her.

I don't know for sure if the Smithsonian was the key to Isabel's development, but she started to communicate more, even if she was still socially awkward. Going out in public became more difficult for us as she began to try to interact with people—there were some embarrassing moments—but we were happy that she was interested in initiating social interactions. At Disney World in Florida, she walked up to strangers and tried to get them to repeat whatever sentence she

was fixated on at the time. She would say something like, "Mickey is a boy," and then, "Mickey is a \_\_\_\_\_." She'd wait for the other person to fill in the blank, a practice she continues today with more complicated sentences. Outside a restroom near Cinderella's castle, she approached a man with a big beer belly, pointed at his stomach, and said, "Baby inside." He wasn't thrilled, but we applauded Isabel for using a preposition. At a hotel swimming pool, she snapped a stranger's bikini top. The woman, less good humored than the pregnant man, lectured Joyce about being a bad mother.

Isabel would take phrases and distort them, sometimes to odd effect. One of these times—more recently—occurred after she had a blood test at a doctor's office when she was ten. She was so terrified of having her blood drawn, even a small finger prick for a typical blood count, that to do so would require several people holding her down while she screamed and flailed. As a result, we delayed one of her booster shots for two years. It was awful to see her this way, acting as if she were convinced she was about to be murdered. We got her to repeat the words "It's just a little finger prick," in the hope that she could reassure herself. After one visit to the doctor, Joyce dropped Isabel off at my office on her way to work. The department faculty, having adjourned from a meeting, mingled in the lobby of the anthropology building as Isabel ran in crying, "My prick is filled with blood!"

By the time Isabel was six years old and we entered the public school system, she knew about 200 words, mostly nouns and proper nouns, and was getting better at school routines. But it would be a tough and extended battle to get the school system to understand Isabel and figure out what type of classroom was most appropriate for her and how to provide it. That's a story better saved for later in this book. Any parent or guardian of a child with a disability already has an idea what that fight entails.

Our story is, in fact, a happy and hopeful one. Isabel has gone beyond what we imagined possible. She's now a teenager—a cellist, a good artist, a caring sister. She adores and takes good care of our two French bulldogs, Linnea and Natasha. She's made Joyce and me better parents, and she's made her sister, Olivia, a better, more compassionate human being. And autism doesn't seem so bad anymore, especially in comparison to the many other tragedies we read about in the newspapers every day.

We're not so embarrassed by Isabel anymore, not because she always acts appropriately in public, but because things have changed so much in American society since Isabel was born. Autism is less a disease to be hidden than a disability to be accommodated; it is less a stigma, reflecting badly on her family, than a variation of human existence. People pity me less for Isabel, and praise me more for her progress. Recently, at a shopping mall, when Isabel acted oddly, I told the

cashier that Isabel had autism. The cashier repeated a romantic and popular idea whose origin remains a mystery to me. “I’ve heard,” she said, “that autistic people are supposed to be very beautiful.” I was stunned that this stranger knew about autism, let alone that she thought about autism so positively. In our community I hear not only about Isabel’s achievements, but about how she contributes to the lives of others. Not long ago the parent of a “neurotypical” (“normal”) child in her grade told me that Isabel had made her son a better person, that her son had learned from Isabel that the concept of diversity isn’t just a positive way to think about racial or ethnic differences, but about differences in learning and intelligence as well.

As time goes on I’m getting more comfortable with Isabel’s disorder, more grateful for who she is and less mournful of the person she might have been without autism. And the difference between Isabel asleep and Isabel awake seems to be getting smaller. I’m comfortable enough now to write a book about her and about autism, something I never expected to do.

To be honest, for most of Isabel’s life, I have had little to say about autism. Like most parents of children with autism, and perhaps any disability or disease, I knew enough. Enough to describe the basics to strangers when she did something embarrassing in public, enough to navigate the educational system in the county where I live, enough to convince doubting family members who insisted that, like Albert Einstein, who is said to have been speechless until the age of six, Isabel would one day outgrow her social and language problems. How much more did I really need to know?

Someone I never met changed my mind. In 1999, I began writing *In the Arms of Africa*, a biography of gifted writer, he made anthropology accessible to readers beyond the ivory tower, in books that were equal parts passion and science, emotion and intellect. As I wrote, I began to talk more about Isabel and autism with my students and colleagues. And the more she crept into my lecture material, the more I recognized that I, too, was trying to make anthropological perspectives understandable and relevant to a general public.

Turnbull used to say that anthropology can be a method both to convey one’s personal involvement in a culture and to teach about the diversity of human experience. This book is guided by Turnbull’s belief that anthropology is about much more than going away to distant cultures. It’s also about coming home and seeing your own world, even your own child, in a new light. It’s about finding that, in the end, the people who can teach you the most might very well be in your own backyard.

Isabel has taught me that the unexpected, even the beautiful, can emerge even from the undesirable, like a

lotus growing out of the mud, its beauty and purity unsullied by its origin. That beauty can be found in a single person, inside of whom there is something—no, not something “normal,” but a brilliant light or an inner truth struggling to blossom.

So when people pity me for my daughter, I don’t understand the sentiment. I work hard for Isabel, but I don’t regret it or feel sorry for myself. At the end of the day, when I tuck her in, she’s not a case of autism, or even a child with social deficits and language delays. She’s simply my daughter. My job is to clear the land for whatever growth is to come, even if, sometimes, no one else believes it will happen, even if

the growth is twisted like the *Corylus* in front of the Smithsonian.

\* \* \*

When Isabel was first diagnosed, the experts we consulted told us that she was lucky to be alive in the 1990s, that in times past she would have been diagnosed with mental retardation or schizophrenia and institutionalized. Autism itself wasn’t new, they said. What was new was the diagnosis and management of the disorder.

Over the past decade, we’ve seen autism move from being a rare disorder to a common one. It seems like the “epidemic” happened overnight. But it actually took decades to arrive. After all, Leo Kanner first identified and named autism way back in 1943. What did he see in the early 1940s that no one else had seen before? And why did it take so long for autism to become well known?

### Stay Warm! Sonnenberg Consultants



Matthew-“Yipee Ocean”