

SUNY UPSTATE  
**Outlook**

News on education, biomedical research & health care at  
SUNY Upstate Medical University • Syracuse, New York

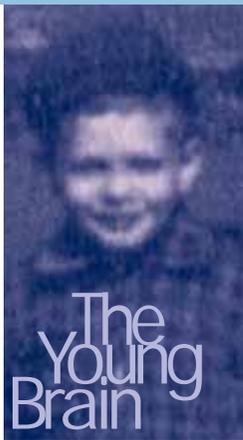
Volume 6, Number 3

Spring 2007



# The Young Brain

At SUNY Upstate, a constellation of the nation's top pediatric minds explore the marvels – and address the missteps – of the developing brain, which remains under construction into early adulthood.



DAVID SMITH, M.D., AGE 4



# SUNY UPSTATE Outlook

## Intercepting Autism

Autism spectrum disorders now affect one in 150 children, making these perplexing conditions a priority at University Hospital.

by Susan Keeter

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## Collateral Damage

SUNY Upstate experts make a compelling case for paying serious attention to Attention Deficit Hyperactivity Disorder.

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## From Bench to Barstool

By chronicling alcohol's impact on brain development, Michael Miller PhD helps to intercept the legacy of alcohol abuse.

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## Making Sure Health Care Cares

SUNY Upstate's new president is a pediatrician by training, a change agent by necessity.

by Denise Owen Harrigan

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## Pay It Forward

A tribute to the late Gregory Keating PhD.

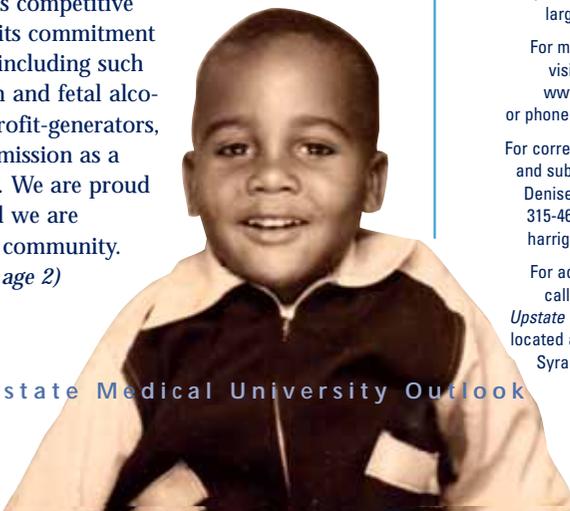
by Denise Owen Harrigan

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## FROM THE PUBLISHER

It is clear from the contents of this issue – as well as from the towering cranes now constructing the Golisano Children's Hospital at University Hospital – that the care (and understanding) of our young is a top priority at SUNY Upstate Medical University. In today's competitive medical environment, Upstate perseveres in its commitment to address the full range of pediatric needs, including such perplexing conditions as spina bifida, autism and fetal alcohol syndrome. These vital services are not profit-generators, but they speak to the heart and soul of our mission as a public hospital and academic medical center. We are proud to stamp these services *Only at Upstate*, and we are committed to keeping them available in our community.

–**Ronald R. Young MBA** (at right, age 2)  
Vice President for Public and  
Governmental Affairs



Spring 2007

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Vice President, Public and  
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University Hospital  
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A close-up, slightly blurred photograph of a baby's face, looking upwards and to the left. The baby has dark eyes and a soft expression. The background is a warm, golden-brown color.

# THE YOUNG BRAIN: **Handle with Care**

Six-month-old Matthew was diagnosed at birth with PKU, an inherited metabolic disease (IMD) which can lead to severe mental retardation. Thanks to his early diagnosis, a special diet and treatment by Joan Pellegrino MD at University Hospital's Center for IMD, Matthew is physically strong, developmentally advanced – and on track for a bright future.

Children are not just small adults, especially when it comes to their brains. These vital-yet-vulnerable command centers remain under construction into early adulthood, shaped by what SUNY Upstate neuroscientist Michael Miller calls “the dual sculptors, nature and nurture.”

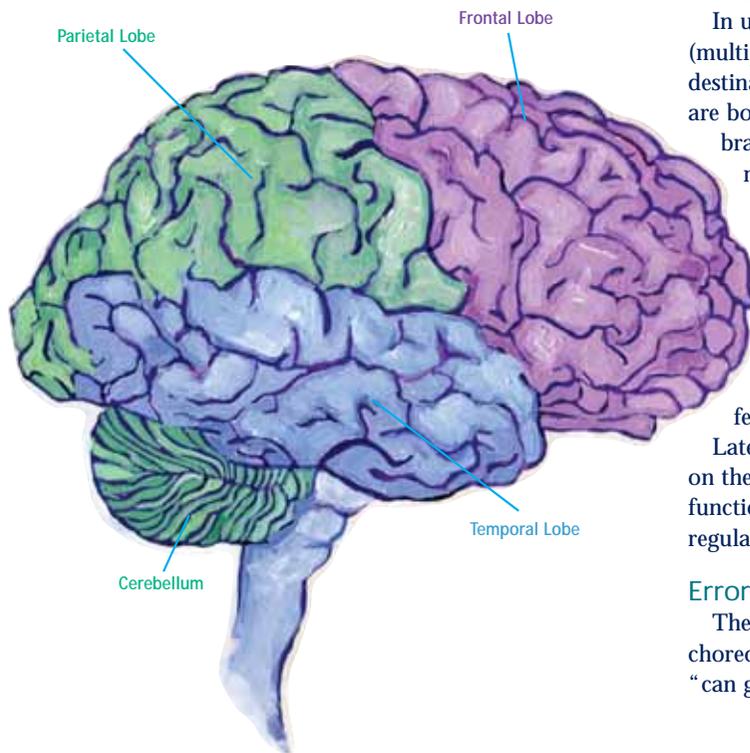
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Gabrielle, Aliashaia and Catherine at a summer camp for burn survivors.

The Young Brain - from page 3

If exposed to injury, illness, toxins –  
and even insufficient stimulation –  
the young brain can be permanently  
impaired. But, with positive input,  
this delicate organ can be primed  
to achieve its highest potential.



### A Matter of Time

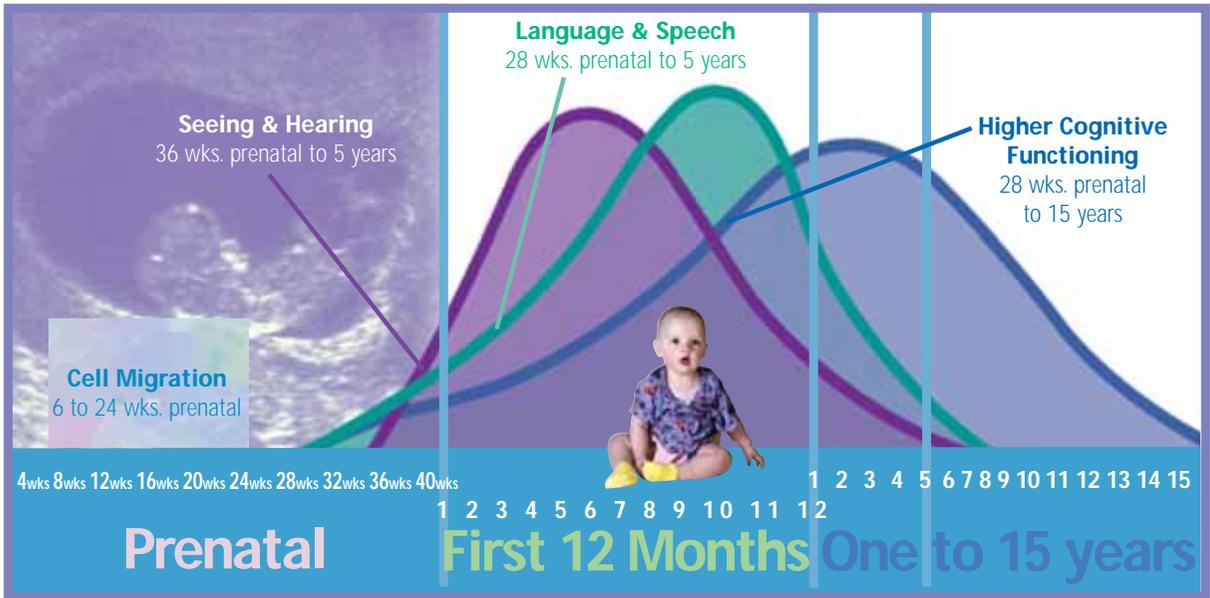
In utero, specific neurons (or brain cells) proliferate (multiply), differentiate and migrate to their final destinations in the neurological network. While babies are born with more than enough neurons – and their brains are almost full size by the age of 1 year – major refinement is yet to occur.

Especially in the first five years of life, the connections between these neurons are increasingly activated and fine-tuned, primarily through myelination: the insulation and fortification of axons that carry information from one neuron to the next. These signals – propelled by electrical activity, or synapses – provoke thoughts, actions, feelings and even memories.

Later, in adolescence, the ongoing refinement is focused on the prefrontal lobe, which orchestrates higher order functions such as planning, decision-making and mood regulation.

### Error Prone

The maturation of the human brain is an intricately choreographed cascade – which, according to Miller, “can go wrong at any stage of the process.” These

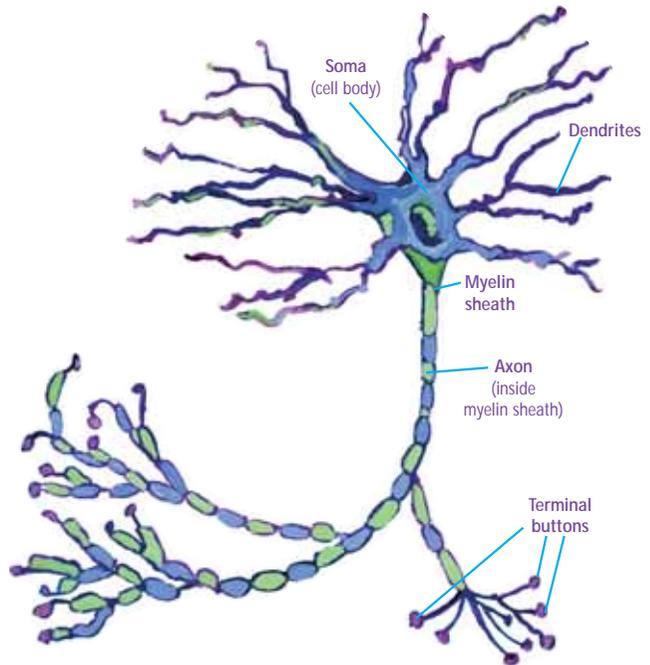


potential missteps make the young brain the focus for hundreds of SUNY Upstate physicians, nurses, scientists, therapists, psychiatrists, psychologists, educators and social workers.

Working within another intricately choreographed system – the academic medical center known as SUNY Upstate – these specialists diagnose and treat pediatric brain diseases and disorders; conduct basic and clinical research; train their medical colleagues; and lead the charge in addressing and preventing these conditions.

In the pages ahead, we look at the young brain under construction – and disruption – from early gestation to late adolescence. We share insights from our experts, who concede that much remains to be deciphered, in terms of normal and abnormal brain development.

These pediatric experts salute the vast progress made in our understanding of the young brain – and in our culture’s acceptance of children with brain disorders. Increasingly, these young heroes are surpassing expectations – and further inspiring those who love and care for them. ■



## AIDAN'S STORY

At 1 year, Aidan was saying “Mommy” and “Daddy.” At 15 months, he was a “picky eater” who refused anything but pureed baby food and milk in a sippy cup. He shrieked when his mother tried to get him to play with finger paint. A familiar PBS children’s show terrified him.

Aidan’s worried parents tried to convince themselves, “It’s probably nothing. He’ll outgrow it.”

Then — at 18 months — Aidan stopped talking.

His parents remember Aidan’s grandmother, a retired day care teacher, saying gently, “I think it’s time to take him to a specialist.” They saw Aidan’s pediatrician and asked for a referral to University Hospital’s Center for Neurodevelopmental Pediatrics.

At University Hospital, they met with developmental pediatrician Louis Pellegrino MD, whom Aidan’s mother described as “very gentle and nice.” He asked questions about Aidan’s behavior and sat with him at a play table, encouraging Aidan to try play therapies that help evaluate development.

Then, cautioning that a definitive diagnosis can be challenging in children under 3 years of age, Pellegrino said, “Aidan is showing autistic tendencies.”

Pellegrino drew the three circles of developmental areas affected by autism: language, behavior and social. He referred the family to the Onondaga County Health Department’s Early Intervention program for a complete evaluation and access to services, stressed the importance of therapeutic interventions, and scheduled a follow-up appointment.

“The diagnosis was a bomb,” admits Aidan’s mother, whose mental image of autism did not match her cuddly son.

continued on page 8



# Intercepting Autism

The numbers are alarming: autism now affects one in 150 children. The causes remain mystifying. But interventions are encouraging.

## AN UPDATE FROM THE AUTISM EXPERTS AT UNIVERSITY HOSPITAL:

Sixty years ago, society blamed 'bad' parents for autism. Stereotypical autistic behaviors – lack of eye contact, repetitive rocking and limited speech – were seen in children traumatized by World War II, leading some 'experts' to falsely conclude that autistic children had been similarly traumatized by their home lives.

### Not So

Today, the medical community recognizes autism as a neurobiological disorder with many causes: geneticists have identified more than 20 genes associated with the condition, and fMRI scans show that young children with autism often have larger brains than typical children.

"Most importantly, we know that early diagnosis and behavioral intervention dramatically influence the outcome for a child with autism," says Gregory Liptak MD, MPH, director of neurodevelopmental pediatrics at SUNY Upstate. Liptak is one of eight physicians who has rewritten the American Academy of Pediatrics' guidelines for Autism Spectrum Disorders.

### What is autism?

According to a recent report from the Centers for Disease Control and Prevention (CDC), autism occurs in one in 150 children in the United States, with more boys affected than girls. It involves delays and impairment in

social interaction, behavior and language. Autism is called a 'spectrum disorder' because it affects people differently and encompasses a variety of conditions including: Asperger's syndrome, pervasive developmental disorder, autism, childhood disintegrative disorder and Rett's disorder.

The causes of autism remain a mystery and its treatment, a challenge. Medical diagnosis is made by observing behaviors, because there is no lab test. Medication is available to treat symptoms associated with autism, but not the primary condition. In terms of intelligence, autistic children range from gifted to severely challenged and, contrary to stereotype, only nine to 12 percent of children with autism never develop speech. Due to extensive learning challenges, many people with autism need some level of support throughout their lives.

### Pediatricians Are Key

"Symptoms can be subtle," admits Liptak, "but screening tools are available and should be part of regular check-ups at pediatric and family practice offices."

In fact, incorporating autism screening tools such as the CHAT and M-CHAT (Checklists for Autism in Toddlers) into doctors' visits is part of the new national pediatric guidelines coauthored by Liptak.

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## Aidan is living proof that “early intervention is key.”

Aidan - from page 6

That evening, Aidan’s mother found several websites including autismspeaks.org, a site recommended by University Hospital. She read about autism, recognized the ‘red flag’ symptoms in Aidan and began the slow process of accepting the probable diagnosis.

Since Aidan’s first appointment at University Hospital two years ago, his mother has become an advocate for children with autism. She attends monthly meetings of the CNY chapter of the Autism Society of America and works on the society’s website. She is knowledgeable about therapeutic interventions for autism and practices them at home with Aidan to reinforce the behavioral interventions he receives from a host of teachers, therapists and health care providers.

Today, 3-year-old Aidan is living proof that “early intervention is key.”

Thanks to a renowned five-day-a-week special education pre-K program in Syracuse and physical, occupational and speech therapy three times a week, Aidan is making excellent progress.

And, his parents have gained a better understanding of his developmental issues, strengths and talents. His mother explains, “Aidan is very bright, and a quick learner, but he needs a focused situation, without distractions.”

Aidan has mastered the alphabet and can count to 30 by placing letters or numbers in proper order. He knows hundreds of words and communicates with two-word sentences like “more eat.”

Non-verbal communication — such as making eye contact or pointing — is a particular challenge for children with autism, and Aidan’s mother is especially pleased about his most recent accomplishment.

“Just the other day,” she said, “Aidan pointed to us and said, ‘Mommy’ and ‘Daddy.’”

“If you have a concern about your child’s development, make the phone call,” Aidan’s mom advises parents. “Interventions – the earlier, the better – will make all the difference in the person your child can become. Plunge in and do everything you can. Learn the therapies. Talk with other parents. Find the best services you can for your child.” ■

Intercepting Autism - from page 7

### Types of Intervention

Behavioral interventions, the most effective treatment for autism, can produce significant improvement in cognition, social interaction and language skills when begun before 5 years of age. Most research is available on “applied behavior analysis” (ABA), in which therapists work one-on-one with a child 20 to 40 hours each week. Other common therapies include DIR or floor time, which is a relationship-based approach, and TEACCH, which is an educational model that focuses on structured learning. Many other therapies are listed on the CDC website.

### Atypical Learners

“Children with autism tend to be strong visual learners with sluggish mental processing,” explains Carroll Grant PhD, director of the Margaret Williams Center, a program jointly supported by SUNY Upstate Medical University and the CNY Developmental Services Office.

“For example, a father asks his son if he wants milk or juice. If that child has autism, the father’s words may be gone before the child can process them. But, show that same child pictures, or actual containers of milk and juice, and the child and parent can communicate.”

### Diet & Vitamins

According to research, 95 percent of parents pursue nontraditional treatments for their autistic children, primarily dietary restrictions and vitamin supplements. The most common are gluten-free (no grains) and casein-free (no milk sugars) diets. Aidan (see page 6) is on a casein-free diet (replacing cow’s milk with soy milk), and his family believes it helps him focus.

### Toxins

Research is exploring environmental causes for the recent increase in autism. (In 2000, autism was identified in one in 2,000 children. Today’s rate of 1 in 150 can be partially attributed to increased awareness and expansion of the definition of autism.)

“Mercury can play a role,” reports Liptak. “Research shows that children who live in contaminated areas are more likely to have autism.”

However, he strongly cautions against pursuing unproven treatments: “Concern about mercury has led to non-FDA-approved use of lead poisoning medication, and children have died.”

Pregnant women are advised to limit intake of fish and other foods that may contain mercury. And, although research has shown no clear link, thimerosal, a synthetic form of mercury used as a preservative, was removed from childhood vaccines in 1999.

### Genetic Research

Much of current autism research focuses on genes and environmental exposures, and their impact on each other. Researchers are looking at how genes alter an individual's susceptibility to environmental toxins and how environmental exposures may alter gene expression.

The 20 genes associated with autism seem to play a large role. If parents have one child with autism, the chance of having a second child with autism rises to 1 in 20. Notes Liptak, "If someone in your family shows autistic tendencies, you are more likely to have autism."

### Community Needs

This year, Upstate's neurodevelopmental pediatrics staff will work with Syracuse University to track the incidence of autism in Onondaga County and assess our community's response.

In December 2006, the \$1 billion Combating Autism Act was signed into federal law. It calls for screening every child in America, \$643 million for research, and tens of millions of dollars for public education. The appropriation process is underway. ■  
—by Susan Keeter

### Red Flags for Autism:

Behaviors that might suggest autism – and merit a discussion with your pediatrician:

- any loss of speech or social skills at any age
- no back-and-forth gestures by 12 months (e.g., pointing)
- delayed or unusual language
- poor eye contact
- unusual or repetitive hand or finger movements
- rigid and limited play interests
- easily upset with small changes

### Increase in Diagnosis

Aidan's diagnosis – regressive or late-onset autism – is the type that has shown a dramatic increase in the U.S. population over the past 10 years. Experts, like SUNY Upstate's Gregory Liptak MD, hypothesize that there may be two conditions with similar autistic behaviors: one in which symptoms appear at birth and a second in which the infant begins to develop typically but shows developmental delays as a toddler.

#### University Hospital's Center for Neurodevelopmental Pediatrics

The Center's role is evaluation, initial diagnosis and referrals, and regular follow-up visits to assess the child's progress with behavioral interventions.

Directed by Dr. Liptak, the staff includes three neurodevelopmental physicians, two geneticists, a nurse practitioner, social worker, speech therapists, occupational therapists and physical therapists. In 2006, the Center saw 250 children with autism, ages 1 to 20 years.

#### Margaret L. Williams Developmental Evaluation Center,

located a few miles from University Hospital, offers evaluation and referrals for children up to age 7; consultation services for children with autism up to 9 years; and outreach support to day care centers and homes. The Center staff includes Dr. Grant, a medical director, a psychiatrist, psychologists, speech/language pathologists, occupational and physical therapists, a special education teacher and nurses. The center follows 300 children with developmental delays, half of whom have autism.

Both centers serve 15 counties in Central New York.



# ATTENTION DEFICIT HYPERACTIVITY DISORDER

## Collateral Damage

At SUNY Upstate, an extraordinary concentration of ADHD experts warn that – left untreated – the misunderstood condition derails lives and predisposes young patients to mood disorders and even substance abuse.

The condition we know as ADHD (Attention Deficit Hyperactivity Disorder) has been clinically observed for nearly 100 years and intensively studied for the past 30. The positive results of stimulant medication for affected children have been known for 70 years. However, it wasn't until the 1990s that awareness of the disease exploded, and ADHD began to be better understood – as well as misunderstood.

### Evidence-Based

ADHD has longstanding acceptance in the scientific and medical community, and an increasing body of neurobiological evidence also shows physical differences in the ADHD brain. But ADHD – unlike other serious psychiatric conditions – has also been “diagnosed” via public opinion.

SUNY Upstate Professor of Psychiatry Michael Gordon PhD, who in 1986 started one of the nation's first ADHD clinics, says he appreciates why people may misunderstand the full impact of ADHD. “To some extent, we've all experienced distraction and lack of focus. It's part of being human.”

But, Gordon points out, ADHD goes far beyond normal distractibility or misplaced car keys.

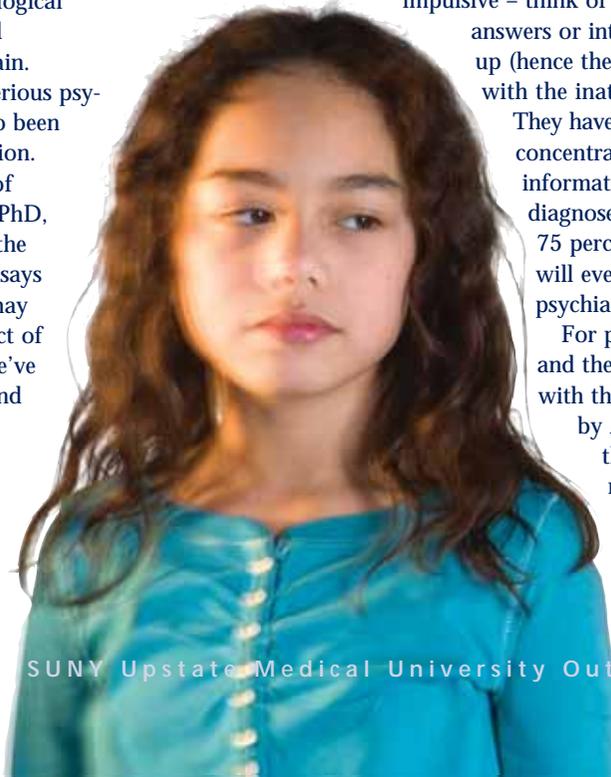
“You can line up a set of ADHD symptoms and people think, ‘oh, I've experienced that.’ What they don't realize is that ADHD is not simply a checklist of symptoms. It is the serious impairment caused by those symptoms that we strive to address.”

### Early & Often

ADHD is the most common psychiatric condition among children, and the one with the earliest onset. Between 3 and 7 percent of American children have the disorder, which is characterized by a lack of inhibition. ADHD kids have problems paying attention and are impulsive – think of the child who blurts out answers or interrupts. They can be wound up (hence the “hyper”) or dreamy (those with the inattentive type of ADHD).

They have problems with organization, concentration and remembering information. Boys are more often diagnosed than girls, and nearly 75 percent of all ADHD children will eventually develop a second psychiatric disorder.

For parents of ADHD children and the professionals who work with them, the impairment caused by ADHD is vexing. Because these children have trouble regulating their activity, the child's behavior – not following instructions, for example – may seem willful, even deliberate.



“Raising typically developing children can be a challenge,” comments Kevin Antshel PhD, assistant professor of psychiatry and director of the Adult ADHD program at SUNY Upstate. “But children with ADHD are even more challenging. It’s been documented over time that the parents of ADHD children experience significant stress.”

### Genetic Link

To compound matters, ADHD is highly heritable. So the parents dealing with an ADHD child may be suffering from the condition themselves. “It is not unusual to diagnose a parent along with the child,” says Antshel.

“Part of successful treatment includes a highly structured environment for the child. If a parent has untreated ADHD, that goal may be next to impossible.”

While children may outgrow aspects of their physical restlessness, problems remain. Adolescents with ADHD are more likely to suffer driving accidents, teen pregnancy and drop out of school. If their condition persists into adulthood – as is likely for 60 percent of them – they are prone to having greater difficulty with work, relationships and even the law.

Of major concern are ADHD’s comorbidities, the other psychiatric problems that march alongside ADHD.



Parents dealing with an ADHD child may be suffering from the condition themselves.

### Heightened Risk

“Only 30 percent of those with ADHD have it alone,” reports Stephen Faraone PhD, SUNY Upstate professor of psychiatry and one of the most widely published authorities on ADHD. “The rest have some combination of other disorders, including Oppositional Defiance Disorder (ODD), anxiety, depression and tics.” He adds that children with ADHD are twice as likely to have conduct disorder, five times more likely to develop a mood disorder, and seven times more likely to have ODD than their non-ADHD peers.

“It doesn’t mean that one disorder is primary and one is secondary,” he says, “but ADHD can be a harbinger of what’s to come. It can allow us to educate patients and parents and screen for problems early.”

A serious problem affecting a higher percentage of teens and adults with ADHD than their peers is substance abuse. “This is among the most feared problems, as it is so difficult to treat.” Faraone said. “The risk starts later, but awareness can allow us to identify and treat those problems very early.”

### Kindling Question

One concern that arises for parents is: will medications taken for ADHD somehow ‘kindle the brain’ and contribute to later substance abuse? “There have been six large studies examining the link between those who take ADHD medication and subsequent substance abuse,” reports Faraone, noting that in three studies ADHD medication provided a protective effect against substance abuse, one study showed a slight negative influence, and two studies were neutral. “Proper medication can protect against substance abuse, as the person with ADHD is less tempted to self medicate with illegal drugs,” he notes.

Another accompanying condition – oppositional defiant disorder – may eventually affect up to 65 percent of children within several years of ADHD onset. ODD is characterized by belligerent and stubborn behavior.



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## Adolescents with ADHD are more likely to suffer driving accidents, teen pregnancy and drop out of school.

Another 14 percent of those with ADHD may develop the more serious conduct disorder, an antisocial pattern of behavior which can include lying, stealing and bullying.

### Family Factors

"We know that some ODD is related to disrupted parenting," notes Russell Barkley PhD, SUNY Upstate professor of psychiatry, noted author and international speaker on ADHD.

"This is when a parent is inconsistent, using indiscriminate punishment, or veering between harsh and permissive. In some cases this disrupted parenting is related to a parent's own ADHD. Between 25 and 35 percent of those parents qualify for ADHD themselves."

In fact, Barkley's studies show that a chaotic family life can accelerate the problems associated with ADHD. "Major depression is more likely to coexist in these families, and the teens are more likely to drop out of school or be involved in a teen pregnancy," he said, adding that students with ADHD drop out of high school at a rate three times above the national average.

Although the recent studies on ADHD comorbidities illustrate the downside to ADHD, the Upstate faculty are quick to point out that many people are coping well and are successful.

"The research shows us where we need to further focus our attention," Gordon says. "We cannot minimize ADHD, nor can we romanticize it. There are people who are very positive about having ADHD, but the reality is that a good diagnosis and good management make all the difference."

### Preferred Treatments

Medication, and medication with therapy, are the preferred treatments for ADHD. The Multimodal

Treatment Study of Children with ADHD, which is the largest treatment study of any childhood psychiatric disorder, showed that these approaches were more effective than therapy alone.

"Stimulant medications are generally a front line strategy, as the effect – if it is going to work – will usually be seen quite quickly," reports Antshel.

"But treatment should be very individualized for the child. One size does not fit all."

Parental intervention – such as reinforcing appropriate behavior, applying consequences for misbehavior, and using time outs – must be consistent between home and school settings to be effective. Interestingly, research shows that social skills training is not terribly effective for children with ADHD.

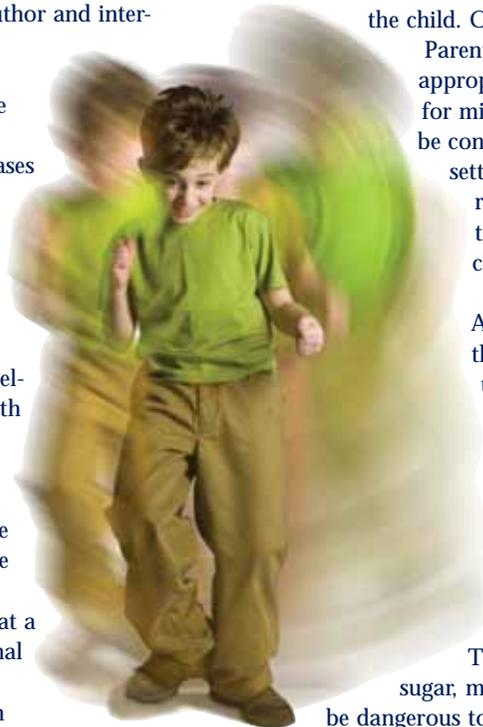
"The kids know how to act," says Antshel. "It's the impulse control that keeps them from being able to use the skills."

The faculty also comment on treatments which are not supported by evidence or discredited through research. "There are parents who are justifiably concerned about the use of medication, but they should also know what is likely a waste of time and money," Antshel said.

These approaches include removal of sugar, megavitamin therapy (which can also be dangerous to the liver), removal of fluorescent lights, sensory motor integration, treatment for inner ear disturbances and vision training.

For parents whose children receive a diagnosis of ADHD, the questions lurk. Is this really a problem or just a feature of my child's personality? Where do you draw the line between natural exuberance and hyperactivity?

"We must ask the first question – is there an impairment?" Gordon concludes. "ADHD isn't about someone who is doing okay but could be doing better. Instead we must ask, is this person functioning less well than others? That's the lightning point for discussion and diagnosis." ■ -by Leah Caldwell





## TOP ADHD EXPERTS UNDER UPSTATE UMBRELLA



Michael Gordon PhD



Stephen Faraone PhD



Russell Barkley PhD



Kevin Antshel PhD

### Michael Gordon PhD

is professor of psychiatry and director of the Attention Deficit Hyperactivity Disorders Program at SUNY Upstate and founder of one of the nation's first ADHD clinics. Widely published in academic journals, Dr. Gordon also authors books for professionals and families. He developed the Gordon Diagnostic System, a standardized test of attention and self-control, as well as the Attention Training System for children.

### Stephen Faraone PhD

is Director of Medical Genetics Research and Head of Child and Adolescent Psychiatry Research at SUNY Upstate. Dr. Faraone is principal investigator on several NIH grants and is one of the world's leading authorities on the genetics of psychiatric disorders. He has produced more than 400 journal articles and is the second-most cited author in the ADHD field.

### Russell Barkley PhD

is a research professor at SUNY Upstate and a pre-eminent authority on ADHD and author of the definitive text *ADHD: Handbook for Diagnosis and Treatment*. Dr. Barkley has authored, co-authored or edited 22 books and nearly 200 papers and chapters. Continuously funded by the NIH since 1978, he has received 14 grants totaling more than \$7 million.

### Kevin Antshel PhD

is a research assistant professor in psychiatry and director of SUNY Upstate's new Adult ADHD Research and Treatment Program. In addition to ADHD, Dr. Antshel has also conducted research in the areas of developmental neuropsychology, learning disorders and autism.



# From Bench to Barstool

By documenting the damage of alcohol exposure in utero, Upstate's Michael Miller PhD helps to intercept the legacy of alcohol abuse.

**M**ichael Miller's eyebrows arch when fetal alcohol syndrome (FAS) is described as the most preventable cause of mental retardation. It's not the cognitive damage he disputes – Miller's FAS research details the often-profound impact of maternal drinking on the developing brain. What he objects to is the unilateral assumption that drinking during pregnancy is “preventable.”

“My perception is that drinking during pregnancy is not always a choice,” Miller explains. “Alcoholism may be a factor in FAS, and alcoholism is not a question of personal weakness. Alcoholism is largely genetic – wired into your internal system during gestation. It's a disease with a biological cause.”

## Co-Conspirators

After decades of laboratory research into FAS, Miller – professor and chair of Neuroscience and Physiology at SUNY Upstate – has seen plenty of data supporting alcoholism as a biological phenomenon. He also contends that dual sculptors – nature and nurture – conspire against children with fetal alcohol syndrome and predispose them to alcohol abuse.

Recently, in the journal *Alcoholism: Clinical and Experimental Research*, Miller wrote that FAS and alcoholism are “inextricably interrelated – indeed they are parts of a self-perpetuating cycle of alcohol abuse.”

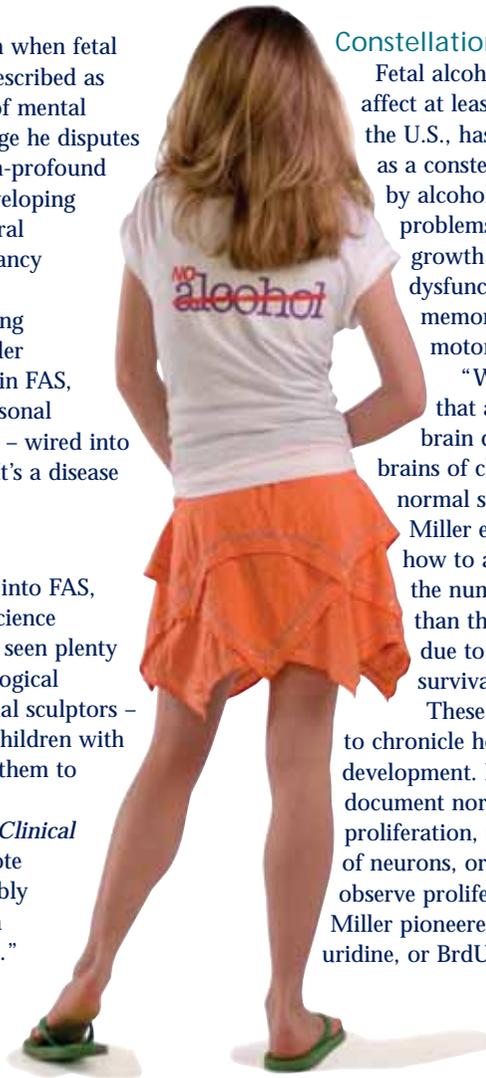
## Constellation of Problems

Fetal alcohol syndrome, estimated to affect at least one percent of live births in the U.S., has been recognized since 1973 as a constellation of problems induced by alcohol exposure in utero. These problems include facial abnormalities, growth retardation and mental dysfunction, such as learning and memory deficits, hyperactivity and motor disorders.

“We've known for some time that alcohol messes up normal brain development, and that the brains of children with FAS are half the normal size, or micro-encephalic,”

Miller explains. “But we didn't know how to account for the difference in the number of brain cells. Were fewer than the normal number produced, due to alcohol exposure? Was cell survival compromised?”

These questions inspired Miller to chronicle how alcohol impairs brain development. His first challenge was to document normal brain development – the proliferation, migration and differentiation of neurons, or brain cells. To stain and observe proliferating cells during gestation, Miller pioneered the use of bromodeoxyuridine, or BrdU.



### Timing: Crucial

Once he'd documented the normal neuron cycle, Miller studied how ethanol, commonly called alcohol, disturbed this process. He discovered that timing is crucial. The impact of alcohol exposure is profound during gastrulation, which occurs at days 27-28 of fetal development. "This is when stem cells are forming protostructures for the body and mapping out the face," Miller explains. "At this point, alcohol exposure reduces the size of certain cranial nerve nuclei in the brain stem and leads to the craniofacial irregularities characteristic of FAS."

Alcohol exposure is also highly disruptive later in the cycle, when neuron cells are migrating. "Neuronal migration is the bridge between the birth of the cell and its proper integration into the final structure" explains Miller. "At this stage, alcohol exposure can have serious consequences for downstream developmental events. A cluster of cells that migrates to the wrong place – heterotopia – can cause dyslexia, epilepsy or schizophrenia."

### High Profile

Most days, Miller can be found in his Weiskotten Hall laboratory, tracking substances like transforming growth factor, or TGF, a versatile protein that helps steer neurons toward maturity. His current research is supported by close to \$4.5 million in national funding, and he has published two books and 110 research papers. In 2005, his painstaking FAS research earned Miller the Henry L. Rosett Award for Lifetime Achievement from the Research Society on Alcoholism.

Eager to make his research relevant in the real world, Miller has joined colleagues (at SUNY Upstate, Binghamton and Cortland and the Syracuse VA Medical Center) to form the Developmental Exposure Alcohol Research Center. With \$2.5 million in research grants,



the 19-member group collaborates on studies which explore how fetal alcohol syndrome primes the brain for alcoholism – and what interventions might decrease this risk.

### Adolescent-Focused

The group is especially interested in adolescence, when brain circuitry is optimized and excess neurons die off. According to Miller, this is a good time to steer clear of alcohol, which can further deplete the reserve of brain cells.

In one of the Center's behavioral studies, Upstate's Steve Youngentob is looking at how adolescents with FAS respond to the smell of alcohol. "It can have a repulsive effect," notes Miller, "but more commonly, FAS is linked to a preference for the smell of alcohol."

In the journal article cited earlier, Miller and coauthor Linda Spear underscore the urgency of clinical intervention before and during adolescence, especially for children with FAS. "Children with FAS are among those initiating alcohol use as young adolescents and with the highest incidence of developing alcohol abuse disorder," they report.

The article recommends development of strategies to delay the time of alcohol initiation, discourage binge drinking and "alter the culture that promotes/glorifies alcohol use."

In addition to adding important insights into our understanding of alcohol use and abuse, Miller says his research sheds light on the origins other developmental disorders, such as autism and schizophrenia, and provides a model for studying the negative effects of nicotine and other toxins. ■

–by Denise Owen Harrigan



Michael Miller PhD

## NEURODEVELOPMENTAL DISORDERS

# The Heart of Pediatrics

No child chooses to have a developmental disability such as spina bifida or autism. But the neurodevelopmental pediatricians who choose to care for these children say they are rewarded, and humbled, on a daily basis.

“I believe what these children show us every day is called courage. It’s amazing how well they do, despite their disabilities and adversities,” says Gregory Liptak MD, MPH, director of University Hospital’s Center for Neurodevelopmental Pediatrics. Ironically, when Liptak was a medical student at Duke University, he avoided a developmental pediatrics elective, because it seemed so depressing. Today he’s considered a national authority on children with developmental disabilities.



### What changed his mind?

Aside from their inspiring resilience, Liptak liked the broad scope of care these children require and the opportunity to forge long-term relationships with the children and their families – something he hadn't considered until he spent five years in emergency pediatrics. Liptak also knew there was a need for developmental pediatricians. Early in his medical career, he earned a master's degree in public health – and developed a broader perspective on gaps in services, especially in pediatrics.

### Lines Blurred

In 2005, University Hospital's Center for Neurodevelopmental Pediatrics had 2,180 visits from children and adolescents in a 15-county catchment area. Their conditions fall under two categories: physical, such as spina bifida and cerebral palsy, and cognitive, such as autism, Down syndrome and ADHD.

But there is tremendous overlap between the physical and cognitive, according to Liptak. For example, children with spina bifida often have hydrocephalus, with learning disabilities that continue into adulthood.

"Many non-medical factors affect the health and well-being of these children," he notes. "This means that we may need to involve speech, physical and occupational therapists, nutritionists, social workers, nurses, orthotists, neurologists, neurosurgeons, urologists, orthopedists, psychiatrists, psychologists and more.

"It's logistically and financially challenging to convene these teams," he says, "especially considering today's health care economics."

### The Bright Side

But there are far more positives than negatives.

"Vaccinations and newborn screenings are the greatest breakthroughs,"

Liptak reports. "I used to see children with rubella syndrome who were blind, deaf and mentally retarded. We don't see that anymore.

"New York State newborn screenings now detect PKU in time to prevent mental retardation," he adds. "With early nutritional therapy, those children now develop normally."

Another major advance, according to Liptak, is society's acceptance of individuals with disabilities. "There's a huge difference in how these children are treated in school," he reports. "They are more integrated into the community and have many opportunities to develop their potential.

"Our understanding of these disorders has also increased," Liptak adds. "I started my practice with a focus on spina bifida, a chronic, incurable condition that is the most complex birth defect compatible with life. But the management of spina bifida keeps getting better and better. Life expectancy is now 40 to 50 years."

### Team Effort

If it takes a village to raise a child, it takes a nation to raise a child with a complex neurodevelopmental disability such as spina bifida or cerebral palsy.

That's why Nienke Dosa MD, MPH, seeks to expand the circle of those who understand the challenging world that her patients, and their families, navigate. "Pediatrics is really a public health specialty," she says. "Nowhere is this more true than for the pediatric patient with a developmental disability."

Dosa often works from the inside out – focusing on the physician to better serve the patient. She has designed a "Parent Partners in Health Education" program that gives residents in pediatrics and family medicine an inside view of the daily life of families raising a child with a developmental disability.

"Family caregivers are the bedrock of our nation's chronic health care system," says Dosa. "Yet rarely is their contribution explicitly recognized. This program teaches future doctors how to collaborate with families."

Under Dosa's new program, residents make two home visits, focusing on the parents as much as the patient. They also visit the child's school, "because so much of what we recommend as doctors," notes Dosa, "is carried out by educators, therapists and other school-based professionals.

"A pediatrician needs to understand systems of care, as well as patient care," she adds. "None of this is rocket science. It's learning what's available in the community and how to collaborate. The new program is

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also empowering for parents, who are paid to spend time with the residents – and pleased to be the focus of attention.”

The program is being piloted at several sites, and New York State hopes to implement it for all its residents.

### Coming of Age

Dosa has also established a research program that targets the transition of patients from pediatric to adult health care. “The vast majority of these kids with complex conditions now survive into adulthood,” she reports. “Our healthcare system needs to catch up with these new patients.

“Young adulthood is a vulnerable time for my patients,” she continues. “Often their parents have been the keepers of their health information. There may be an element of learned helplessness. Our new program, recently funded by New York State, helps these young adults – and their physicians – develop the tools for this transition.”

### Learning about Learning

Spina bifida and cerebral palsy are the most medically complex disorders treated at the center, but cognitive disabilities such as autism are the most common – and most commonly addressed locally by Louis Pellegrino MD, who was “hooked” by developmental pediatrics during residency (“It’s what’s at the heart of pediatrics,” he believes).

Pellegrino completed two fellowships in the specialty, at University Hospital and Strong Memorial Hospital in Rochester, and came back to Upstate in 2004.

“Learning and cognitive disorders can be due to many causes,” he explains. “Sometimes they run in families

(e.g., reading disorders are often familial). Sometimes they can be due to a genetic defect (such as Down syndrome). But often there is no obvious medical cause.

“Kids with developmental issues are often bigger than one field or profession,” Pellegrino notes. “For me, part of the draw is rubbing shoulders with people outside of medicine, especially teachers.”

Routine or mild cognitive disabilities are often addressed by primary care physicians, “General pediatrics is shifting toward the developmental and behavioral,” says Pellegrino who attributes the rising diagnosis of learning disabilities to better awareness and detection.

“But kids’ lives today are also more complex,” he adds. “They’re under more pressure, which may lead to more of the behavior problems that can accompany ADHD and other disorders.”

### Defining Disability

Pellegrino sees many patients with disabling learning disorders. He concedes that the term ‘learning disabled’ is elusive. “The diagnosis can depend on how disabling the condition is to the patient,” he says. “We are all born with different brains, with more potential for some things than others. We come with certain innate skills, strengths and weaknesses.

“Neurodevelopmental pediatrics,” he adds, “is not a good field for those uncomfortable with ambiguity.”

Pellegrino’s patients often have more than one medical diagnosis, since learning disabilities – such as autism or ADHD – often have comorbidities, such as anxiety, depression or obsessive compulsive disorder.

“Our evaluations for learning disabilities are very comprehensive, in terms of looking at the child’s abilities, skills and behaviors,” Pellegrino reports.



Gregory Liptak MD, MPH;  
Louis Pellegrino MD;  
Neinke Dosa MD, MPH of  
Neurodevelopmental Pediatrics  
at University Hospital

“We take very detailed histories, interview families and review developmental records, school records and school testing and perhaps do a little of our own testing.

“With all that information in front of me,” Pellegrino says, “I make a diagnosis, which is just a small part of the detailed report we share with parents, referring physicians and school districts.

“Recent advances, such as functional magnetic resonance imaging (fMRI), have given us a much better idea of which parts of the brain are doing what – of what’s going on under the hood,” Pellegrino says. “But even better are the studies that show which interventions make a difference.”

School districts are mandated by law to make the necessary accommodations. “We draw attention to the problem, and hopefully kids will get the support they need.

“A big part of my role is advocacy,” he adds. “We help parents find that support for their kids. I see a lot of gaps in services but also pockets of excellence. If these kids can get the help they need, they are generally very resilient.” ■

## APPLAUSE, APPLAUSE

It’s not unusual to cheer when a child takes his first steps, but the applause was deafening when 9-year-old Romeo, of Fort Drum, finally walked through the halls of his Watertown elementary school. In a wheelchair since he was a toddler, Romeo had orthopedic surgery last year at University Hospital, to help release tendons tightened by spina bifida. Three months later, his schoolmates were lining the halls to applaud his first steps.

With a heart as big as his legendary namesake, Romeo has been charming Central New York since his family came to Fort Drum in 2003. Before their transfer, the US Army made sure that the region offered the specialized medical resources required by patients with spina bifida. At University Hospital’s Center for Neurodevelopmental Pediatrics, Nienke Dosa MD, MPH, now orchestrates the complex team of specialists helping Romeo to thrive. “From our first visit,” reports Romeo’s mother, “Dr. Dosa and her team took us under their wing and made all the wheels turn.”

This spring, Romeo’s father – a helicopter mechanic – will be deployed to Iraq. “Ordinarily, we’d go home to Michigan to wait for him,” says Romeo’s mother. “But Romeo’s making so much progress that we’re staying right here.”



# Good News, Bad News

There is good news about kids with cancer: today more than 80 percent survive.

But there is also sobering news for these courageous kids, especially those who beat brain tumors and leukemia. Many of them will grapple with cognitive complications – and struggle to keep pace with their peers.

Often these deficits – commonly known as “cognitive late effects” – are caused by treatments that saved these children’s lives. Intracethal chemotherapy, for example, injects harsh chemicals into the spinal fluid surrounding the brain. Surgery and radiation to the brain can likewise damage this vulnerable, still-developing organ.

“Some of these kids seem to be doing okay a year or two after treatment,” notes Nan Songer MS, educational specialist at University Hospital. “But after three or four years – when school becomes more challenging, and these children are not progressing at the same rate as their peers – the problems are obvious.”

These delayed cognitive deficits underscore the importance of the longitudinal monitoring offered by the Kids Now Off Therapy (KNOT) clinic at University Hospital’s Center for Children’s Cancer and Blood Disorders.





The KNOT clinic sees cancer survivors at least once a year, well into adulthood. When a cancer survivor shows signs of cognitive late effects, an entire team of medical and learning specialists – from University Hospital and Syracuse University – steps forward to evaluate, make recommendations and advise the child’s school district.

### Progress Interrupted

Late effects often become most noticeable in middle school, when the academics grow more challenging, and students are expected to be more independent.

Under normal circumstances, the brain rises to these challenges with appropriate developmental advances in areas such as processing speed and attentiveness. For years, the young brain has been prepping for this increased workload, primarily by strengthening the insulation (or myelin sheath) around the axons that carry messages between brain cells.

But when children are treated for cancer, especially brain tumors or leukemia, this myelination can be delayed or diminished by chemotherapy or radiation. Surgery to remove a brain tumor can also cause long-term problems. The prefrontal lobe – the last area to be fine-tuned – is especially vulnerable.

“These kids get to middle school, and the cognitive load increases,” explains Songer. “But their cognitive ability doesn’t keep pace. They especially struggle with math, abstract thinking and processing speed.

“Often these kids are labeled with behavioral issues,” she adds. “It’s their way of masking learning problems – better to seem out of control than to be considered stupid.”

Cognitive late effects are even more evident in the teen years, when executive

function, such as mood regulation and time management – fail to fully develop.

“Our older patients often have issues related to higher-order brain functions – impulsivity, poor behavioral inhibition, responding appropriately in social situations and peer relations in general,” explains Songer.

### On Alert

The good news is that these late effects are increasingly recognized and addressed by both medical and educational professionals.

“Twenty years ago, these kids fell through the cracks,” reports Sue Shaw NP, director of the KNOT clinic. “I have one new patient, in her 30s, who had three years of cancer treatment as a child. At first, she was an A student.

Then she got Bs, then Cs. She had no explanation for the decline. She didn’t go to college. As an adult, she interpreted her memory problems as early-onset Alzheimer’s.

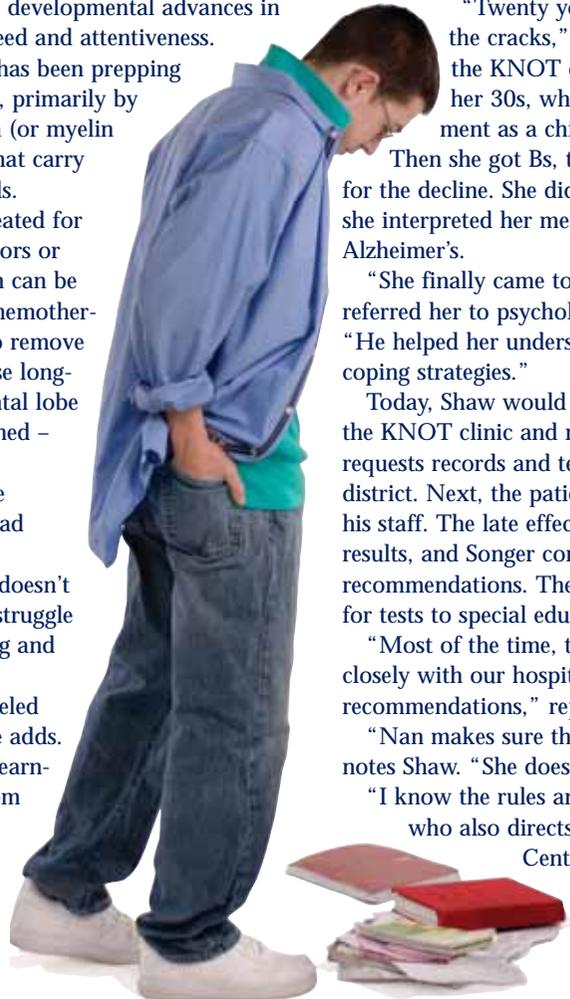
“She finally came to the KNOT clinic, and we referred her to psychologist Brian Rieger,” Shaw reports. “He helped her understand her late effects and suggested coping strategies.”

Today, Shaw would be alert for such challenges in the KNOT clinic and make a referral to Songer, who requests records and test scores from the child’s school district. Next, the patient is tested by Rieger or one of his staff. The late effects team then reviews all the results, and Songer contacts the school district with recommendations. These may range from extra time for tests to special education services.

“Most of the time, the school districts work closely with our hospital team and implement our recommendations,” reports Songer.

“Nan makes sure these kids get what they need,” notes Shaw. “She doesn’t go away.”

“I know the rules and regulations,” concedes Songer, who also directs the Early Childhood Direction Center at Syracuse University.



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## IT TAKES A VILLAGE



Nan Songer MS  
Education Specialist  
SUNY Upstate Medical  
University



Brian Rieger PhD  
Psychologist  
Physical Medicine and  
Rehabilitation  
SUNY Upstate Medical  
University



Susan Shaw PNP  
Director  
KNOT Clinic, Pediatric  
Hematology/Oncology  
SUNY Upstate Medical  
University



Rebecca Gath  
Doctoral Student  
Syracuse University

**T**he line between medical and educational support often converges when it comes to children and cancer, or any long-term illness. It truly takes a village of health care and educational specialists, working in concert, to keep these children educationally on track.

University Hospital has created a nationally recognized network of specialists to help patients with cognitive late effects. The team includes Nan Songer MS, educational specialist; Brian Rieger PhD, psychologist; and Sue Shaw NP, director of the Kids Now Off Therapy (KNOT) clinic. Also contributing are doctoral students and Professor of Psychology Larry Lewandowski PhD of Syracuse University.

Together they test, evaluate and create treatment plans for patients with late effects – and run interference with school districts. One of the team's most critical roles is teaching teachers about late effects – and how to tailor education plans to help these children succeed. Recently, the team published a paper in the *Journal of Pediatric Hematology and Oncology*. The paper describes their web-based education modules, which were developed (and validated) to teach teachers about the academic consequences of childhood cancer.

The modules are available at [www.upstate.edu/peds/cancerintheclassroom/](http://www.upstate.edu/peds/cancerintheclassroom/).

# A Banquet for Hungry Minds



## OASIS NOURISHES THE AGING BRAIN

Is there anyplace to turn for support in halting or reversing the effects of aging on your brain? A place that offers a strategy for claiming greater control over your mental fate as you grow older? A place that can tap into your experience and interests, awaken unrealized potential and trigger a mental renaissance?

Yes, there is – and it’s called OASIS. With centers in 26 cities, OASIS is a national, non-profit organization designed to enhance the quality of life for mature adults, age 50 and over. Its programs are based on sound science and an engaging premise: the more you use your brain, the bigger it becomes and the better it works. We now know that if you continue to learn and challenge yourself, your brain continues to grow, literally. And we know that exercise and brain-healthy nutrients are equally essential to that process. The OASIS model addresses each of these requirements for a healthy brain.

“OASIS centers traditionally partner with department stores, health care providers and other community organizations to reach as broad an audience as possible,” explains Lauren Feiglin, director of the

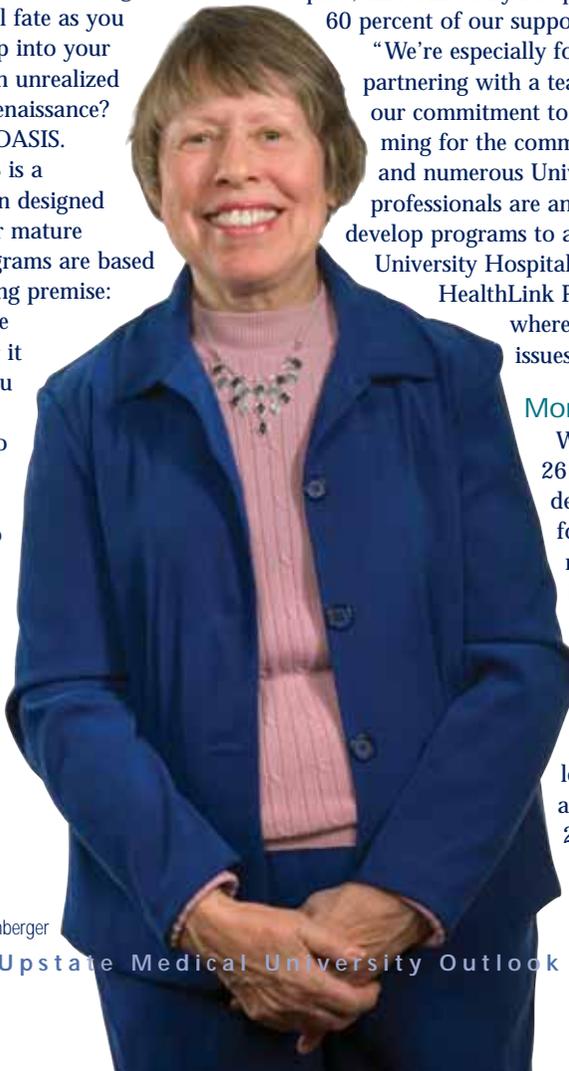
Syracuse center since its opening in 2001. “The major sponsors of our chapter are Macy’s, which provides the space, and University Hospital, which provides about 60 percent of our support.

“We’re especially fortunate,” says Feiglin, “to be partnering with a teaching institution that shares our commitment to health and wellness programming for the community. Dr. Sharon Brangman and numerous University Hospital health care professionals are an invaluable resource as we develop programs to advance our mission.”

University Hospital has also located its HealthLink Program in the OASIS center, where it offers seminars on health issues to the entire community.

### More Than Courses

With 360,000 members in 26 cities, OASIS has been described as “a banquet hall for hungry minds” – for good reason. In its open and inviting quarters in ShoppingTown Mall, in DeWitt, the Syracuse chapter’s nearly 7,000 members satisfy their thirst for learning, fitness and health through courses, lectures, hands-on experience and field trips. “In the fall 2006 trimester,” Feiglin



Anita Weinberger

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OASIS - from page 23

We are an intelligent species and  
the use of our intelligence quite  
properly gives us pleasure.

reports, “nearly 1,100 of our 6,700 members were enrolled in one or more of the 125 courses we offered, for a total of more than 3,000 enrollments.”

Each trimester, about 70 percent of the center’s courses fall into the categories of art and humanities, personal development and enrichment, nature and science, computer skills and volunteering. The remarkable array of subjects includes art history, music history, film history, world affairs, Spanish, oil painting, piano lessons, creative writing, story telling, computers and digital photography—to name a very few.

At OASIS, retired educator Anita Weinberger discovered not only “a wide range of courses taught by the very best professors and artists in the area,” but the opportunity to volunteer as a teacher of a music course that helps grandparents learn songs to sing with and to their grandchildren — “a great experience for me,” Weinberger recalls, “and, I hope, for those who participated.”

For Peggy Owens, a retired school teacher, OASIS means more than courses. “It is a chance to meet new people, learn new things, and break the isolation that traps so many people later in life,” she says. “It is a way to stay challenged and make new friends.” Owens, in fact, traveled to Egypt with a friend she met in OASIS. Later, their trip became part of a course in which the pair shared their experiences.

### No Boundaries

Courses in health and fitness, including at least one nutrition course, account for about 30 percent of each trimester’s offerings, providing members opportunities to gain and retain the physical skills that are no less vital to mental health than intellectual stimulation.

The OASIS Institute in St. Louis developed HealthStages for Personal Growth and a Healthy Lifestyle, a comprehensive program that helps OASIS members address their changing health needs proactively. As described by Jacqueline Jackson-Young RN, BSN, HealthStages administrator in the Syracuse center, “the program offers a variety of health and wellness opportunities, from exercise and fitness, to personal growth and managing existing health conditions. Members are encouraged to let us know of any health-related courses they would like to see offered.

“In practical terms,” she continues, “keeping the aging brain healthy boils down to ‘use it or lose it,’ and every form of stimulation — audio, visual, and kinetic — is relevant and productive. We touch all the bases at OASIS, realizing there’s no magic

Jack Houseworth

In this respect the brain is like a muscle.  
 When it is in use we feel very good.  
 Understanding is joyous.

—Carl Sagan, *Broca's Brain*

wand. One of the messages we try to convey is taking charge of your body, listening to your body, being intuitive.”

In the fall 2006 trimester, HealthStages included courses in rhythmic walking, yoga, aerobics, strength training for men, swing dance, whole food nutrition and hiking tours in the Adirondacks. Also included was a range of non-traditional courses, including the Alexander technique, Zen meditation and T'ai Chi. “When it comes to brain health,” says Jackson-Young, “there are no boundaries, and the inclusion of nontraditional approaches is essential to the comprehensive program we strive for.”

### Anything but Apathetic

Growing enrollments and the expansion of programs and courses have been steady markers of success for the Syracuse chapter, which has also taken on an ambitious outreach program. In the fall 2006 trimester, courses were offered in Syracuse at Artist Pianos, the Jewish Community Center, Syracuse University and White Crane Studio. Courses and volunteer programs were also given at Baltimore Woods, Cathedral Academy, DeWitt Community Library, Greenpoint Senior Living, Liverpool Library and Traditions at the Links. Five hundred people were enrolled in 21 courses offered at 10 offsite locations.

The success of OASIS, in Syracuse and nationwide, reflects profound demographic trends, as well as a sea change in perceptions. Jack Houseworth, a retired architect who serves as vice chair of the Syracuse chapter's Advisory Council, reflects, “The stereotype for an older person has changed dramatically, and OASIS is helping to change it. Program leaders find that OASIS members enjoy learning, participating and growing together — they are anything but apathetic. The ShoppingTown center is an active, school-like environment, where mature students enter with excitement and anticipation and exit with fulfillment and joy.”

Good science, an engaging premise and impressive results. The positive effects of active membership in OASIS may be anecdotal, but at the very least they reflect recent findings in neuroimaging: the brain can rewire itself, even in old age, adding new cells in response to stimulation, exercise and nutrition. If we know how to care for our brains, there's no reason most of us cannot sustain our emotional and intellectual balance throughout our entire lives.

OASIS is the place to put this knowledge to the test. ■

—by Thomas Raynor

Peggy Owens



# Making Sure Health Care Cares

Upstate's new president is  
a pediatrician by training,  
a change agent by necessity.

**T**en months after he started practicing pediatrics in Brownsville, Tex., David Smith MD testified before the Texas state legislature, with pictures of a baby who died during childbirth. "This is what happens," the young pediatrician told the lawmakers, "when the system doesn't care."

Health care that didn't care was new to Smith, who had trained at the world-class Cincinnati and Philadelphia children's hospitals. But in Brownsville – where Smith had been sent by the National Health Service Corps, to care for migrant children – he encountered the opposite end of the pediatric spectrum.

"It was essentially occupied Mexico," he says, "with desolate conditions and diseases you only read about."

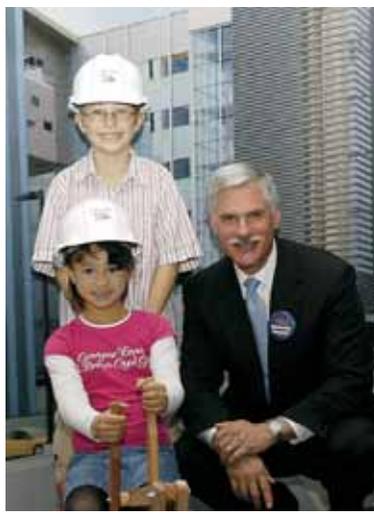
Even more unsettling was the indifference of some health care providers. In the case of the dead baby, Smith alleged that a Brownsville hospital had pressured the baby's uninsured mother into the arms of a midwife, who was ill-equipped for the difficult delivery.

## Collision Course

Smith refers to the Brownsville years as his Southern Exposure, because – as in the TV series *Northern Exposure* – his Ivy League education collided head-on with rural reality.

"I considered myself really medically and culturally competent," he remembers. "I could take a history, do a physical, run tests, confirm or rule out a diagnosis and write a prescription. I could even do it in Spanish.





President Smith with Jacob and Mariah at last fall's dedication for the vertical expansion/ Golisano Children's Hospital at University Hospital.



"But I couldn't be sure that babies were delivered safely," Smith says, "because I couldn't force hospitals to admit patients without insurance. And I couldn't cure kids with parasites, because they would go home, take their medication and then drink the same contaminated water that made them sick in the first place."

That's when Smith and his wife, pediatrician Donna Bacchi MD, first understood the difference between health care and medicine. "We could only go so far, practicing medicine with individual patients," Smith says. "We realized we could make a bigger difference working as advocates for the voiceless and powerless."

### Grace Under Pressure

Before Brownsville, Smith's plan was to complete another residency in pediatric anesthesia and critical care pediatrics. He had discovered, as chief resident and director of a medical transport team (and earlier, playing hockey) that he performed well under pressure.

Good thing, because Smith's testimony in Texas inspired passage of the 1985 Indigent Health Care Bill – and death threats against his family. Undaunted, Smith became medical director of the Brownsville Community Health Center – and a member of the Board of Education, where he ordered an audit that exposed a \$21 million embezzlement scheme. "It didn't make sense to me," Smith remembers, "that a school with 700 children had only 72 books in its library."

Ultimately, the Brownsville experience changed the course of the Smiths' lives. "I think all doctors should have an opportunity to serve in such a setting," he says. "You realize that pediatrics goes well beyond the delivery of care to a child. Children don't vote. The pediatrician has to be an advocate for the child and often for the family. You have to develop very different skill sets. You have to learn to understand the family, the community and the culture, or you're not going to be successful."

### Dr. Smith Goes to Washington

With advocacy now a family priority, in 1987 Smith accepted an invitation to become chief medical officer for health centers operated by the Department of Health and Human Services in Washington, DC. High on his agenda was shelter-based healthcare for the homeless. Bacchi, meanwhile, earned a master's degree in public health at Johns Hopkins University and advocated for the vaccine compensation injury act.

Then came an intriguing invitation from Parkland Memorial Hospital in Dallas, one of the nation's largest and highest rated public hospitals. Parkland had been thrust into the national limelight in 1963, when its trauma team tried to save President John F. Kennedy. A quarter century later, Parkland was making headlines for tackling the upstream issues – such as lack of primary care – that drove patients in crisis to its overcrowded emergency department.

### "House Calls"

Now, Parkland was inviting Dave Smith to create a more proactive, holistic, community-based primary care network. It was a logical, yet revolutionary, new paradigm that was later featured in Bill Moyers' 1993 book *Healing and the Mind*.

In his interview with Moyers, Smith explains the rationale for taking health care to the patient, instead of bringing the patient to the hospital. "It doesn't make good business sense to keep paying for making sick people well," he explains. "If we can prevent a stroke that's going to come to \$100,000 in intensive care costs, doesn't it make sense to invest \$200 a year in health maintenance? One way or another, you're going to pay."

### Health Care, In Context

With Smith as CEO, Parkland set up seven neighborhood clinics, where health care teams, including social

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## As president of SUNY Upstate, Smith feels focused, balanced – and ready to exercise all of his medical muscle on behalf of Central New York’s health care needs.

Making Sure - from page 27

workers and nutritionists, followed the example of family docs and considered at all the factors – financial, social, emotional, cultural, spiritual – that affect health and health care compliance.

Partnering with patients – instead of just prescribing treatment – is one of Smith’s mantras. “It’s a therapeutic partnership,” he explains. “As you engage a patient, there are things going on in the brain, different neurotransmitters and different chemistry, that change when one is engaged in one’s own health. It has been proven to help in the healing process.”

### Shots Across Texas

In 1992, Smith returned to public service, serving as Texas Commissioner of Health under Governor Ann Richards, then George W. Bush. “It was a fascinating time in a fascinating agency,” says Smith, whose Shots Across Texas campaign increased vaccination rates by 20 percent and landmark anti-tobacco lawsuit won \$17 billion.

In 1996 – the same year he was awarded the American Medical Association’s highest honor for outstanding public service – Smith changed gears and became president of Texas Tech University’s Health Science Center and dean of its medical school. He liked the dual challenge of shaping tomorrow’s medical culture while addressing immediate health care needs. On his watch, the academic medical center tripled its federal research funding, doubled its nursing enrollment, established a \$12 million nursing home modeled after a teaching hospital, launched a pharmacy school and much-needed medical school on the Texas/Mexico border and raised \$150 million to enhance academics and research.

### Academics vs. Athletics

In 2002, Smith became chancellor of the Texas Tech University system, with 31,000 students and a \$1 billion annual budget. He saw an opportunity to make Texas Tech’s academic culture as strong and visible as its

athletic culture. “We wanted to establish a counter culture,” he says. “Our goal was to make Texas Tech the most student-oriented university in Texas.”

As chancellor, Smith orchestrated a 40 percent increase in funding for endowed scholarships and 350 percent increase in funding for endowed faculty chairs. “I liked being back in state policy,” he says, “but I missed the public health piece. I never stopped asking myself, ‘How do you rationalize what you’ve done with your medical training?’”

### Homecoming

When he threw his hat into the ring for the Upstate presidency, Smith felt a familiar gravitational pull – toward its soon-to-be constructed Golisano Children’s Hospital. He also felt the geographical pull of the Northeast. He and Bacchi, who met as undergraduates at Cornell, were raised here and have many friends and family in the region.

As president of SUNY Upstate, Smith feels focused, balanced – and ready to exercise all of his medical muscle on behalf of Central New York’s health care needs. He sees an immediate need to grow Upstate’s academic programs, in response to the state’s changing demographics. He wants to increase the volume of Upstate’s voice in health care policy and advocacy. (Smith was recently named by the March of Dimes as spokesman for a national campaign to prevent premature birth and appointed to the NIH National Center of Minority Health and Health Disparities.)

The early days of his Upstate presidency – like his early days in Brownsville – have brought unexpected challenges. But he welcomes the chance to respond to the Berger Commission’s recommendation that University Hospital merge with Crouse into a 500-600 bed hospital.

“I’m an old hockey player who’s never been afraid of a good fight,” he reminds us, “as long as it’s for the right reasons.” ■

# Big-Picture Pediatrics

The gentle soul of a pediatrician and steely resolve of an activist join forces in Dr. Donna Bacchi Smith, who often believes that changing the system is the best medicine.

**L**ike a touchstone, Brownsville keeps coming up in conversations with Donna Bacchi Smith MD, MPH. That's Brownsville, Texas, where Bacchi and her husband, David Smith MD, first practiced pediatrics.

It was 1984, and the Smiths had been dispatched, by the National Health Service Corps, to work with Brownsville's migrant families.

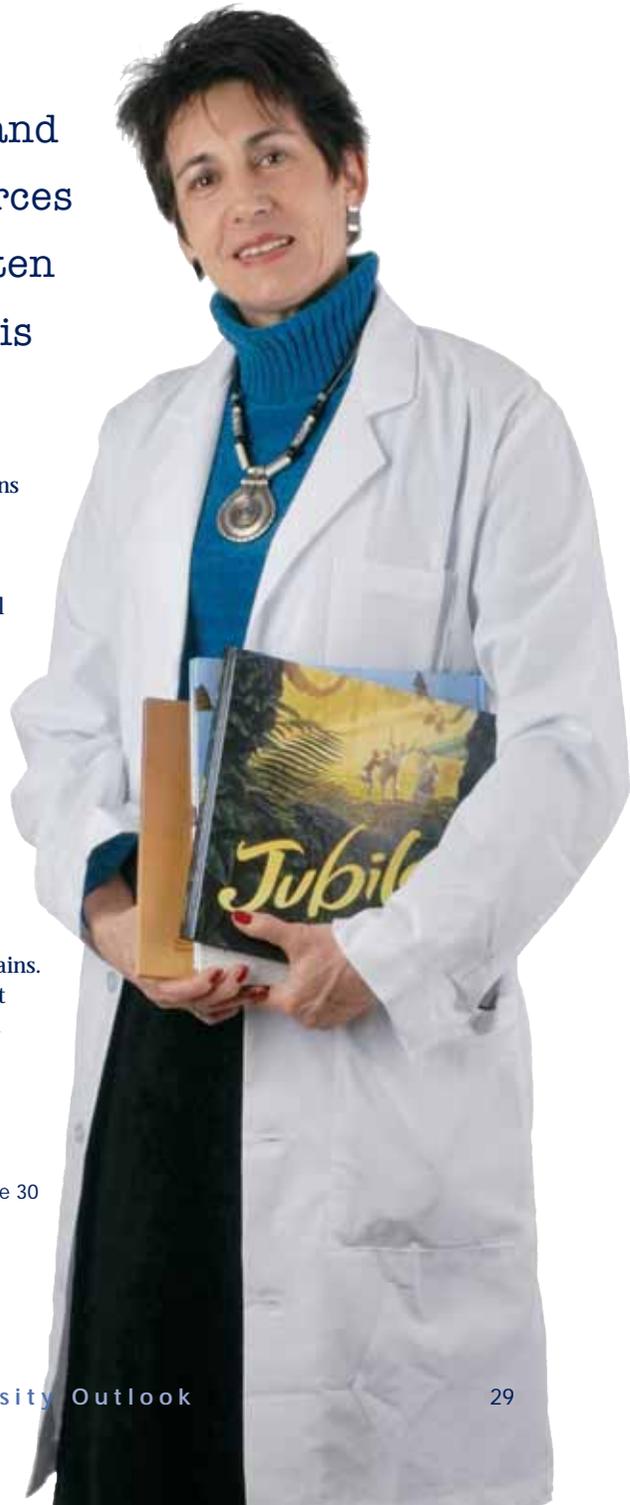
It was an abrupt awakening. "Every medical student should see medicine from this perspective," says Bacchi, still incensed by Brownsville's third-world living conditions. "Our patients were legal U.S. residents, living as if they were in Africa or interior Mexico. No running water. No electricity. No sewers. When it rained, the kids played in contaminated puddles and kept coming back to the clinic with parasites and other third-world diseases."

## Broader Lens

Until then Bacchi was inclined to fault patients for medical non-compliance. "I had trained at a large tertiary care facility," she explains. "I made judgments based on what I saw in the examining room. But after Brownsville, I looked beyond – at what families had to endure.

"Brownsville changed both of our paths," Bacchi says. "It was frustrating but very rewarding work, and it sparked my interest in public health."

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## Brownsville made her realize that unhealthy choices were not always choices.

Big-Picture - from page 29

### Early Intervention

Proactive by nature – and a nutrition major at Cornell – Bacchi viewed pediatrics as an opportunity to help children and their families make healthy choices. But Brownsville made her realize that unhealthy choices were not always choices.

She began to look at healthcare from a different perspective. “I knew I could continue to see 40 to 50 patients a day in the clinic,” she says, “or I could work for changes, such as installing sewers, that could impact hundreds of thousands.

“But to do that, I needed new tools,” notes Bacchi.

In 1987, when the Smiths moved to Washington, DC, to work for the Department of Health and Human Services, she earned a master’s degree in public health at Johns Hopkins University.

### Prescribing Policy Change

Since then, Bacchi has simultaneously practiced pediatrics and grappled with the issues that endanger children – from seat belts to secondhand smoke, folic acid deficiency to sporadic primary care.

In Brownsville, Bacchi collected data on the alarming number of children she saw with congenital malformations. When scientists began linking these conditions to folic acid deficiency, Bacchi helped campaign for adding folic acid to commercially baked bread.

“A solution was that simple,” she notes.

At Parkland Memorial Hospital in Dallas, Bacchi helped to establish a mobile medical van that brought primary care to the homeless. She is not timid about enlisting support – to keep the van rolling in Dallas, Bacchi helped to raise hundreds of thousands of dollars. When producer Oliver Stone was in town filming *JFK*, Bacchi invited him to premiere the movie locally. The proceeds equipped the van with a Class D pharmacy.

### Close to Home

In Austin, Bacchi embraced school-based health clinics and imported the Reach Out and Read program, launched by a colleague in Boston. She also stepped up her antismoking efforts. By then, Bacchi had watched her son struggle with asthma and lost her mother to lung cancer.

“The fight against smoking became a passion,” Bacchi explains. “My mother died before she really knew her

grandchildren. She never had a chance to enjoy retirement with my father. All because of a disease that could be prevented.”

Bacchi became the driving force behind smoke-free ordinances in Austin and Lubbock, Tex., where she raised \$125,000 by personally recruiting medical groups to join the fight.

Her fervor propelled Bacchi to high-profile health advocacy posts, including president of the American Heart Association in Texas and multiple assignments to national committees.

### Synergistic

One of Bacchi’s research studies looks at students and smoking. So she is pleased by the synergy between her advocacy and SUNY Upstate’s leadership role in creating a smoke-free environment.

In fact, there is much common ground between Bacchi and SUNY Upstate, including the Golisano Children’s Hospital, now under construction at University Hospital.

Bacchi is also a native New Yorker who grew up on Long Island and met her husband at Cornell University.

### Room to Grow

And while Central New York is not Brownsville, Tex., Bacchi sees ample room to make a difference.

She is an associate professor in the Department of Pediatrics at SUNY Upstate and working with the Onondaga County Health Department as maternal and child health director. “I’ll be involved with all the issues that affect moms and babies,” she reports, “including alarming pockets of high infant mortality in Syracuse.”

On the smoking front, Bacchi will work to ban smoking in cars in which children are passengers. “We have precedent with the seatbelt law,” she says. “Do you know that there are 53 cancer-causing chemicals in cigarettes – and concentrations of those chemicals are higher in secondhand smoke?”

“Even if you smoke outside, the gasses stick to your clothes,” she adds. “In terms of cancer, those gasses are the most harmful elements.”

These hard-hitting facts have transformed Bacchi from ardent advocate to outright activist. “When I’m fighting for patients, or when I get solidly behind something,” she notes, “I go full steam ahead.” ■

# Pay It Forward

## IN MEMORY OF GREGORY KEATING PHD

**D**uring Black History Month this winter, fourth-year medical student – and Sarah Loguen scholar – Signa Perkins went to LeMoyne Elementary School in Syracuse to talk about what it takes to succeed in medicine. When she asked the youngsters, “How many of you plan to become doctors?” about 75 percent of the hands went up.

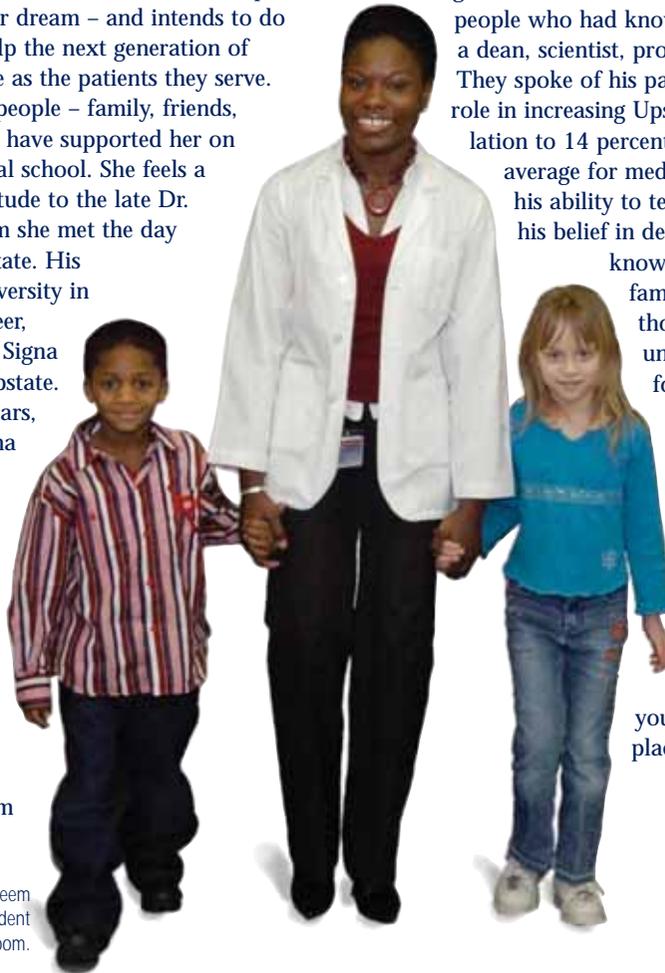
Signa believes in their dream – and intends to do whatever she can to help the next generation of physicians be as diverse as the patients they serve. She knows how many people – family, friends, teachers and mentors – have supported her on the long road to medical school. She feels a particular debt of gratitude to the late Dr. Gregory Keating, whom she met the day she interviewed at Upstate. His genuine interest – in diversity in general, and in her career, personally – convinced Signa that she belonged at Upstate.

For the next three years, Dr. Keating helped Signa navigate every intersection in her medical education. “I stopped in his office or emailed him with endless concerns,” she says. “He had a way of making you feel that you were of utmost importance. When I started medical school, I introduced him

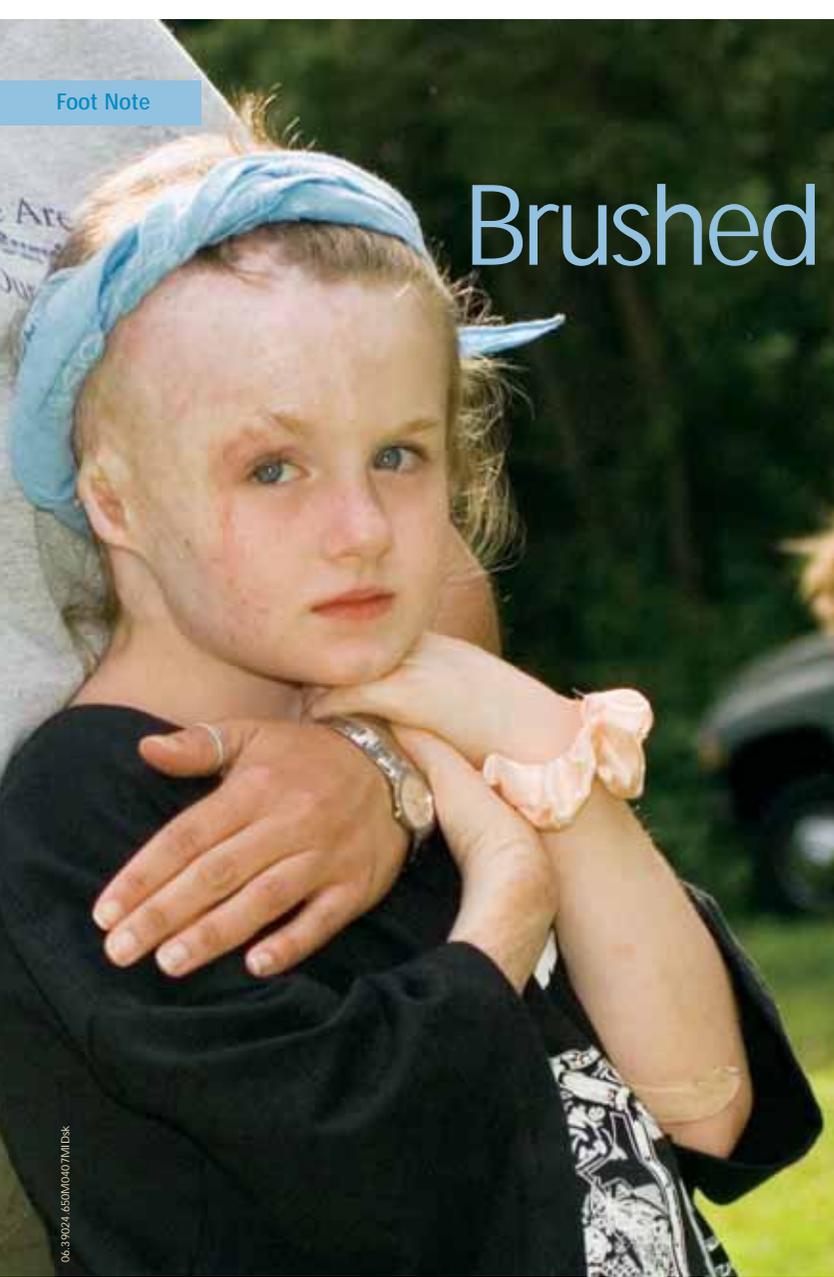
to my parents. What started as a meeting with the dean of students ended as an afternoon among friends. Later, whenever I made a decision about my career, my father would ask, “So what does Dr. Keating think?”

At Dr. Keating’s memorial service last summer, Signa’s sentiments were echoed by more than 500 people who had known the gentle educator as a dean, scientist, professor, colleague or friend. They spoke of his passion for diversity and his role in increasing Upstate’s minority student population to 14 percent, well above the national average for medical schools. They spoke of his ability to teach “the *aha* moment” and his belief in developing balance – between knowledge and empathy, between family and profession. Above all, those touched by Dr. Keating understood their obligation to follow his example and pay it forward.

That’s what Signa Perkins was doing this winter, when she visited the elementary school, planting seeds of hope and nudging students toward bloom. “What I learned from Dr. Keating,” she says, “was to never stop trying to make your environment a better place to be.” ■



Second-grade students Raheem and Alyssa escort medical student Signa Perkins to their classroom.



# Brushed by Angels

This issue of *Upstate Outlook* is dedicated to the inspiring courage of our pediatric patients at University Hospital, exemplified by Arianna, left. A toddler when she was caught in an apartment fire six years ago, Arianna suffered smoke inhalation and massive third-degree burns. She was given less than a 25 percent chance of survival. Today, Arianna is a third-grader who likes swimming, dancing and school. This photo was taken at a summer camp for burn survivors, founded and staffed by her University Hospital nurses and local firefighters.

Arianna's photo, by photographer Susan Kahn, won first place in a biannual competition sponsored by the National Association of Children's Hospitals and Related Institutions ([www.childrenshospitals.net](http://www.childrenshospitals.net)). This, and photos of six other University Hospital patients, appear in an exhibition that will travel throughout the nation and arrive in Syracuse this spring.

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