

# Gazette Gazette

News of Hamaspik Agencies and General Health

**SEP. 2016** • ISSUE NO. 142

⊕ (

# **GAZETTE SURVEY**

The GAZETTE asks YOU:

WHAT PERCENT OF YOUR MONTHLY INCOME GOES TOWARDS HEALTHCARE?

A: Under 10 percent, B: 10-39 percent, C: 40-64 percent, D: 65+ Respond to: survey@hamaspik.org

### **HEALTH STAT**

210,000 U.S. CANCER DEATHS, 1950 591,000 ..... u.s. cancer deaths, 2014

: Source: Data Brief, National Center for Health Statistics. Aug. 24 HEALTH QUOTE

"IT TAKES YEARS ... TO DEVELOP A NEW DRUG. IN THIS SORT OF GLOBAL HEALTH EMERGENCY, WE DON'T HAVE TIME."

—Johns Hopkins Prof. Hongjun Song, on finding two existing compounds that stop Zika virus activity in the body

0.

### **HEALTH TIP**

FOR A GOOD NIGHT'S SLEEP, FIRST RELAX BY READING, SHOWERING AND THE LIKE. Avoid heavy foods, caffeine and electronic devices a good hour before bedtime. Bedrooms should be cool, quiet (phone-free!) and dark.

# ● ► INSIDE

# HEALTH

12

What makes babies cute?

### DISABILITY

02

Georgia defends segregated special ed

### **AUTISM**

06

First U.S. airport "Quiet Room" opens in Myrtle Beach, South Carolina

### **SENIOR HEALTH**

16

For long life, family trumps friends

# HAMASPIK NEWS

05

Top OPWDD advisor visits Hamaspik

# **PUBLIC HEALTH AND POLICY**

03

Public servants address personal data, modern medicine

► PUBLIC POLICY NEWS

# TAKING A STAND FOR FACTS

WITH VIRUSES LIKE ZIKA AND OTHERS, NOTHING SPREADS LIKE FEAR (REMEMBER THE "SWINE FLU" SCARE?)—AND NOTHING PROTECTS LIKE FACTS. CONTROL OF ZIKA-BEARING MOSQUITOES—DUMPING STANDING WATER AND AVOIDING ZIKA-HEAVY STATES AND COUNTRIES—COUNTERACTS THE "HYSTERIA VIRUS" SPREAD BY PURPOSELY SENSATIONAL ZIKA VIRUS REPORTS. SEEN HERE AT A CITY NEWS CONFERENCE IN JUNE, NEW YORK CITY MAYOR BILL DE BLASIO LAYS OUT THE BASICS.



# ● ► PUBLIC POLICY NEWS

# EpiPen Maker Endures Public Backlash After Recent Drastic Price Hike SEE PAGE 04.>>

● ► HAMASPIK NEWS

# Families' Robust Advocacy Secures State Approval of Two New Homes for Eight Sons

**● ► HAMASPIK NEWS** 

# Highest Users of State Mentalhealth Services Getting Farreaching New HARP Program

HAMASPIK OF ROCKLAND AMONG HUDSON VALLEY PROVIDERS OF PROGRAM'S SUPPORT SERVICES

For those New Yorkers who struggle most with chronic and serious mental illness, the vicious cycle of mental illness and social failure, maddeningly, is all too inevitable.

And of those individuals, the ones who most-frequently use state mental-health services to cope with that vicious cycle is something that New York State health officials have long known about.

But with HARP, and the professional counseling

and employment support that it provides, the New York State Dept. of Health (DOH) and other state agencies hope to help those highest-usage individuals in a new and more effective way—treating not just their symptoms but resolving underlying causes... and ultimately breaking that tragic vicious cycle.

# HELPING THE NEEDIEST

The Health and Recovery Plan (HARP) program emerged in 2014 out of Gov. Andrew Cuomo's Medicaid Redesign Team (MRT), a state consortium of public- and private-sector leaders tasked with improving Medicaid.

The HARP program targets those individuals CONTINUED ON PAGE 07 >>

HAMASPIK GAZETTE SEP. 2016 • ISSUE NO. 142

# Services Provided by **NYSHA AGENCIES**

# **OPWDD**

### **COMMUNITY HABILITATION**

Providing: A personal worker to work on daily living skill goals

### **HOME BASED RESPITE**

Providing: Relief for parents of special needs

### AFTER SCHOOL RESPITE

Providing: A respite program for after school hours and school vacations

### DAY HAR PROGRAM

Providing: A day program for adults with special needs

### SUPPLEMENTAL DAY HAB PROGRAM

Providing: an extended day program for adults with special needs

**CAMP NESHOMAH** Providing: A day program for children with special needs during summer and winter school

### INDIVIDUAL RESIDENTIAL **ALTERNATIVE (IRA)**

Providing: A supervised residence for individuals who need out-of-home placement

# INDIVIDUAL SUPPORT SERVICES

Providing: Apartments and supports for individuals who can live independently

# **ENVIRONMENTAL MODIFICATION**

Providing: Home modifications for special needs individuals

# SUPPORTED EMPLOYMENT

Providing: Support and job coaching for individuals with disabilities to be employed and to maintain employment

# **ENHANCED SUPPORTED EMPLOYMENT**

Providing: Job developing and coaching fo people with any type of disability

# MEDICAID SERVICE COORDINATION

Providing: An advocate for the individual to access and coordinate available benefits

# **HOME FAMILY CARE**

Providing: A family to care for an individual with special needs

# INTERMEDIATE CARE FACILITY

Providing: A facility for individuals who are medically involved and developmentally delayed

Providing: Intensive Behavior Services

# **PLAN OF CARE SUPPORT SERVICES**

Providing: Support for families of individuals with special needs

# **FAMILY SUPPORT SERVICES**

Providing: Reimbursement for out of ordinary expenses for items or services not covered by

# TAI RETREATS

Providing: Getaways and retreats for parents of special needs individuals

# DOH

# TRAUMATIC BRAIN INJURY

Providing: Service Coordination · Independent living skills training · Day programs · Rent subsidy · Medical equipment · E·Mods · Transportation · Community transmittal services · Home community support services

# **CHILD & ADULT CARE FOOD PROGRAM**

Providing: Breakfast · Lunch · Supper · Snac

### **EARLY INTERVENTION**

Providing: Multidisciplinary and supplemental Evaluations · Home and community Center based services · Parent/child groups ·

Ongoing service coordination

· Physical therapy · Occupational therapy · Speech therapy · Special education · Nutrition · Social work · Family training · Vision services · Bilingual  $providers \cdot Play \ therapy \cdot Family \ counseling$ 

### CARE AT HOME

Providing: Nursing · Personal care aide · Therapy · Respite · Medical supplies · Adaptive technology

# **NURSING HOME TRANSITION** AND DIVERSION WAIVER PROGRAM

Providing: Service Coordination · Assistive technology · Moving assistance · Community transitional services · Home community support services · E·Mods · Independent living skills Positive behavioral interventions · Structured day

### **LHCSA - HAMASPIKCARE**

### **PERSONAL CARE & SUPPORT SERVICES**

Providing: Home Health Aides · Homemakers Personal Care Aides · Housekeepers · HCSS aides

### **COUNSELING SERVICES**

Providing: Dietician/Nutrition counselors · Social

### **REHABILITATION SERVICES**

Providing: Physical therapy  $\cdot$  Speech therapy  $\cdot$  Occupational therapy  $\cdot$  individuals

### PACE-CDPAP

Providing: Personal care aides for people in need

### SOCIAL AND ENVIRONMENTAL SUPPORTS

### SOCIAL MODEL

Providing: A social day program for senior

### **NURSING SERVICES**

Providing: Skilled observation and assessment · Care planning  $\cdot$  paraprofessional supervision  $\cdot$  clinical monitoring and coordination  $\cdot$ Medication management · physician·ordered nursing intervention and skill treatments

# **HAMASPIK CHOICE**

A Managed Long Term Care Plan (MLTCP) approved by New York State

# **HCR**

# **ACCESS TO HOME**

Providing: Home modifications for people with physical disabilities

# **RESTORE**

Providing: Emergency house repairs for senior

# **HOME REHABILITATION PROGRAM**

Providing: Remodeling dilapidated homes for low income home owners

# **NYSED**

# **VOCATIONAL REHABILITATION SERVICES**

Providing: Employment planning  $\cdot$  Job development  $\cdot$  Job placement

# JOB COACHING

Intensive and ongoing support for individuals with physical, mental and/or developmental disabilities to become employed and to maintain employment

# **NYSHA**

# ARTICLE 16 CLINIC

Providing: Getaways and retreats individuals · Parent

# TRAINING

Providing: Physical therapy · Occupational therapy  $\cdot$  Speech therapy  $\cdot$  Psychology  $\cdot$  Social work  $\cdot$  Psychiatry  $\cdot$  Nursing  $\cdot$  Nutrition

# CENTRAL INTAKE

Providing: The first contact for a person or family in need of Hamaspik services

# HAMASPIK GAZETTE

Providing: A bilingual monthly newspaper informing the community of available Hamaspik

# ◆ DISABILITY NEWS

# In Legal Battle over **Georgia Disability** School System, It's the Feds vs. the South Again

Guess some things don't change. Or at least not that fast.

It's a half-century after the civil-rights era that ushered in racial integration, and 60 years after the Brown vs. Board of Education verdict that kicked off national public school desegregation.

It's also 150 years since the Civil War, which not only pitted North vs. South over human rights but also over state autonomy vs. federal authority.

But modern-day Georgia, once a bastion of independent Southern spirit, is currently fighting another battle with those far-off feds in Washington—this time over what the U.S. Dept. of Justice (DOJ) asserts is nothing less than flat-out disability discrimination.

The case revolves around the Georgia Network for Educational and Therapeutic Support (GNETS), the state's unique system of so-called psychoeducational schools.

The separate system, which provides specialized schools exclusively for students with behavioral and emotional disabilities, is the only public-school system of its kind in the

Because its students largely have no contact with typical students and are also overwhelmingly black, the GNETS system raises the specter of past discrimination. Enter the DOJ's civil rights division.

Following an investigation, the DOJ noti-

fied Georgia educational officials in July 2015 that illegal segregation had been found in GNETS. That same investigation also found substandard facilities without libraries, gyms, science labs and other commonplace features.

The past eight months have seen state and federal lawyers communicating and negotiating over various proposals and counterproposals, but neither side budging on its key position.

Georgia said it has the right to run its school systems as it sees fit. The feds said no. And now, the DOJ is filing a lawsuit claiming that Georgia is violating the civil rights of GNETS students.

"We have determined that we must pursue the United States' claims in federal court to vindicate the rights of thousands of affected students with behavior-related disabilities across Georgia," wrote DOJ civil rights division head Vanita Gupta to Georgia Gov. Nathan Deal in August.

The lawsuit accuses Georgia of violating the Americans with Disabilities Act (ADA). which—among many other things—requires students with disabilities to be educated as often as possible in as typically-integrated a school setting as possible.

According to attorneys familiar with the case, the DOJ will seek nothing short of closing the 24 GNETS program.

# **Millions Headed To States For Special Ed Training**

In mid-August, the U.S. Department of Education announced grants totaling \$7 million across seven states to help them recruit and train teachers and administrators to serve children with disabilities.

The federal grants will fund state efforts towards enhancing preparation and professional development focused on early intervention, special education and transition services.

Specifically, the funding will help support a variety of projects, including recruiting and retaining special education teachers and training on ways to help students with disabilities access the general education curriculum.

In order to qualify for the funding, federal officials said that states must partner with a college or university, at least one school district and a parent training or resource center in order to implement their professional development program.

"It is critical that we support our nation's educators and elevate the teaching profession by supporting strong teacher and principal preparation and professional development," U.S. Secretary of Education John King said in announcing the funds. "These awards help educators learn practices that will improve outcomes for all children, including children with disabilities."

Grants ranging from about \$530,000 to nearly \$1.5 million are headed to Colorado, Louisiana, Mississippi, Nebraska, New Jersey, North Carolina and Oregon.

SEP. 2016 • ISSUE NO. **142** HAMASPIK GAZETTE

# ● ► PUBLIC POLICY NEWS

# The Washington Senator, the FDA Head, the Data Silo and the Heartbeat Wristwatch

HIGH-PROFILE PUBLIC OFFICIALS ADDRESS INTERSECTION OF PERSONAL DATA, MODERN MEDICINE

Besides being influential public servants in positions of power over American health policy, Sen. Elizabeth Warren (D-Mass.) and FDA leader Robert M. Califf, M.D. have another thing in common: They both recently took to respected publications to independently call for modern medicine to harness the enormous and still-growing power of personal health data.

In an August 4 editorial in the leading New England Journal of Medicine, Sen. Warren, long a proponent of healthcare improvement, dwells on data sharing—specifically, free trade of and access to the raw and nameless banks of numbers that result from

clinical trials

The Massachusetts Senator argues that data from clinical trials and other medical studies should be shared with researchers across the industry, with an eye toward facilitating more independent research.

Sen. Warren even opines that medical publications should require researchers to agree to share their data with industry peers before even considering their research for publication. "This requirement would be

a significant step forward in improving the transparency of clinical trials for consumers and the academic medical community," she writes.

The general non-accessibility of research data between research entities is the "silo effect" whose eventual elimination is the goal of Vice President Joe Biden's current cancer "moon shot" effort.

The Vice President's initiative aims to foster universal access to cancer research data across the field of independent researchers. Sen. Warren's editorial applies that concept to all of medical research.

"Data sharing has incredible potential to strengthen academic research, the practice of medicine, and the integrity of the clinical trial system," Sen. Warren posits. "I look forward to following these proposals as they continue to develop and urging their implementation."

Pressing for progress in another corner of the vast intersecting vistas of public health and data is the Food and Drug Administration's Dr. Robert M. Califf.

"We are now entering a new era in medicine that is characterized by dramatic accelerations in biological and information sciences and near-ubiquitous uptake of social media and personal devices," Dr. Califf recently editorialized in the Journal of the American College of Cardiology.

The FDA head invokes today's world, in which more and more people are surrounded by all sorts of personal electronic gadgets, and not just cell phones, that can record every bit of personal vital health data, including heart health.

As far as Dr. Callif sees it, that disconnected jumble of heart health data can—and should—be fused into one seamless system that allows today's cardiology to take a bold leap into a high-tech future.

According to Califf, a flood of quality patient heart data is waiting for the tapping.

"Dramatic improvements in the rate, quantity, and quality of evidence generation are within reach," he wrote. "Almost all Americans now have electronic health records, and social media combined with wearable devices are opening new frontiers in patient- and population-level data. When combined with modern informatics and computing resources, this rich tapestry of information will enable a true paradigm

CONTINUED ON PAGE 13 >>

● ► DISABILITY NEWS

# As Caregiving Parents Age, States Moving to Fund More Residential Services

Seniors with Adult Children with Disabilities Face Waiting Lists, Fears for Future

Along with the still-growing Baby Boomer population of seniors reaching retirement age, another group of American seniors is growing in number in recent years: aging parents of children with intellectual disabilities who live with them at home.

The situations they face are dire.

Often in their late 60s but sometimes well into their 70s or 80s, these older mothers and fathers are typically the only ones providing daily care for their dependent sons or daughters.

For their part, these children with disabilities have typically lived in their parents' homes their entire lives, remaining largely the same as siblings grew up and moved on.

And nowadays, with the passage of decades, these parents are increasingly worrying about who will care for their children when their own time comes.

An estimated 860,000 older Americans currently care for adult children with disabilities at home.

Many of those adults with disabilities are on state waiting lists for additional Medicaid services for people with disabilities, and in many states, their names often remain on those lists until caregivers fall ill or pass away—at which point they typically end up in institutions.

Since the movement away from institutions changed the country in the 1970s and 1980s, most people with disabilities and Medicaid benefits also are being cared for at home by family members.

Another watershed first came in 2013, when Medicaid spending on communityand home-based services exceeded spending on the traditional institutions, mental hospitals and nursing homes. That same year also saw 14 states reporting no large state-run institutions for people with disabilities. Non-institutional care is significantly less expensive, research has shown.

In 2013, according to the University of Colorado, average annual institutional care costs per individual ranged from about \$129,000 a year in Arizona to about \$603,000 in New York.

By contrast, the average annual cost of community-based services per individual is \$43,000.

Despite the progress, aging-parent caregivers face fewer residential options and longer state waiting lists today.

According to University of Minnesota research, about 198,000 people were waiting for home- or community-based services in the 34 states that reported data in 2013. The longest waiting lists were in Ohio (41,500), Illinois (23,000) and Florida (22,400).

But as the number of American seniors providing disability home care grows, some states have passed laws giving them some choices on where, and how, the person they care for will live when they are no longer there to provide care.

A 2015 law in Tennessee ensures that anyone with an intellectual disability and a caregiver over 80 gets the services they need. The Tennessee law was expanded in 2016 to cover caregivers over age 75.

A similar law passed by Connecticut in 2014 covers caregivers over age 70.

Other states like Pennsylvania are planning to fund more Medicaid-funded home

care aide services for aging caregivers by using taxes on natural gas, tobacco and vaping.

According to Bernard Simons, a six-state disability veteran currently serving as deputy secretary for developmental disabilities in Maryland, how well a state addresses the issue depends not on its politics but on its officials' knowledge of the issue, or how much influence is wielded by disability advocates.

When aging parents pass on or fall ill, Simons says, adult children are frequently left with no plan in place, resulting in the aforementioned institutionalization.

According to Susan Parish, director of the Lurie Institute for Disability Policy at Brandeis University, states could alleviate the growing public-policy problem by providing more services and supports to athome family caregivers.

These supports should center on helping the aging caregiver transition out of their caregiver role—by finding their loved ones housing, money, benefits and, most importantly, a new guardian.

What the future holds for this segment of the senior population, and their beloved dependents, is uncertain.

But if the trend of senior-oriented support services continues, what's true for Tennessee and Connecticut may become true for more states, too.

And, if the University of Colorado's numbers hold up, that trend will be a fiscal no-brainer for the states, too.

# **Hamaspik Gazette**

© '06'16 All Rights Reserved

Published Monthly by NYSHA, Inc.

Distributed free USPS Presorted Non-profit Mail

Postmaster: Return service requested



EXECUTIVE DIRECTOR: Meyer Wertheimer SUPERVISOR: Pinchus Weinstock EDITOR: Mendy Hecht
TEL: 845-503-0213 FAX: 845-503-1213

MAIL: Hamaspik Gazette, 58 Rt. 59, Suite 1,
Monsey, NY 10952

E4 HAMASPIK GAZETTE SEP. 2016 • ISSUE NO. 142

### ● ► PUBLIC POLICY NEWS

# EpiPen Maker Endures Public Backlash After Recent Drastic Price Hike

Congress, AMA Urge Cost Cuts; Mylan Partially Blames Insurers, Others

If you haven't heard of an *epinephrine auto-injector*, that's because that's not EpiPen, the name by which most people know it

The life-saving medical device, an item the size and shape of your average marker, is comprised of a dosage of liquid medication, a button-activated injector mechanism, and a needle.

For someone going into *anaphylactic shock*, a life-threatening allergic reaction to anything from bee stings to food, a rescuer need only uncap an EpiPen, press its tip against the upper arm or thigh, push the button—and the auto-injection mechanism does the rest

A single EpiPen device cost about \$57 in 2007. It costs about \$600 today.

# RIGHT DRUG, RIGHT PLACE, RIGHT TIME

The ubiquitous EpiPen—something every ambulance, school nurse's office and parent of a child with a severe allergy (including your *Gazette* editor) has on hand nowadays—is made by Mylan, a company formerly based in the United States but now headquartered in the Netherlands.

In 2007, Mylan bought the EpiPen drug/dispenser combo, and several other medications, from pharmaceutical giant Merck.

In a series of savvy business moves over the coming years, Mylan turned a product that had been giving Merck some \$200 million in revenue into a device that's synonymous with allergic-reaction first-response, much like Kleenex became synonymous with facial tissues.

But unlike facial tissues, which are produced and sold by many companies other than Kleenex, only Mylan makes epinephrine auto-injectors. EpiPen has virtually no competition—giving Mylan a practical monopoly on its life-saving drug and delivery device.

That fact is one of several that have allowed Mylan to currently generate about \$1 billion in annual revenue from EpiPen.

Mylan's industry monopoly was also protected by its patents on EpiPen, preventing any other company from offering the public an alternative. (While those patents have since expired, viable competitors have yet to come forward.)

At the same time, years of strategic national marketing and public-relations campaigns convinced the American public that the danger of people, particularly children, going into anaphylactic shock is greater than it actually is—hence creating a greater demand for the EpiPen devices that weren't necessarily needed everywhere and still aren't.

(A good part of that PR campaign included paying a well-known public figure with an allergic child to serve as the face of an awareness campaign entitled "Anaphylaxis for Reel".)

Those campaigns took a quantum leap forward after a watershed rule change by the FDA back in 2008.

Until then, then FDA only allowed Mylan to market EpiPen to people with medically documented anaphylaxis—in plain English, to people who would have life-threatening reactions to allergens. Post-2008, the federal regulatory agency allowed Mylan to market EpiPens to people who might have life-threatening reactions—opening floodgates of alarmist pitches and resulting national sales.

Another FDA decision that drove up EpiPen sales was its 2010 guideline update that allergy patients prescribed epinephrine for emergency preparedness should also be prescribed two doses of 0.3 mg, not one—meaning that pharmacies should supply patients with two EpiPens, not one.

The change prompted Mylan to start selling EpiPen exclusively in packs of two each.

And the fact that President Barack Obama, himself the father of the peanut-allergic Malia Obama, signed H.R. 2094 (a.k.a. the School Access to Emergency Epinephrine Act) into law in November of 2013—not to mention the public's still-prevalent perception that EpiPen is far more critical than it actually is—only further cemented that monopoly.

That law ushered in several watershed changes.

Firstly, it encouraged public schools to have EpiPens on hand in case of allergy emergency. Until then, EpiPens would only be in nurses' offices if a student had a known severe allergy.

Secondly, it allowed anyone, not just first responders and nurses, to use the fairly foolproof devices—and protected them from any legal fallout should they have used them in good faith.

All of the above, especially the 2013 EpiPen school law, were aided and abetted by the fact that EpiPen has a roughly 12-month shelf-life—meaning that after a year, you have to throw out that old EpiPen and get a new one.

Fueled first by access to vast new markets and then by exclusive access to America's vast public-school system, Mylan's EpiPen sales and profits kept rising—along with the auto-injector's price.

### **PAYING THE PRICE**

While EpiPen's cash price without insurance was already high, and got even higher with Mylan's latest increase, the company has long provided eligible consumers with a number of discounts and "specials."

Mylan offers free EpiPens to patients who are both low-income and uninsured. It offers a \$100 discount card for eligible patients with private insurance. But members of Medicare and Medicaid aren't eligible for that card.

Mylan also has a program that distributes free EpiPens to schools.

According to the company, its EpiPen-4Schools program, which launched in 2013, has distributed over 700,000 free EpiPens to over 65,000 schools nationwide, or about half of all U.S. schools.

But the people most feeling the sting of the latest EpiPen price hike are those who have the lower-quality private insurance plans that feature high-deductibles—meaning, in plain English, that you have to pay quite a bit out-of-pocket for wide range of medications and medical services before your insurance plan starts paying the rest. Among those things are EpiPens; people on high-deductible plans are still likelier to pay over \$500, even with a Mylan discount card.

Compounding that problem is the fact that the number of high-deductible private insurance plans has risen significantly since 2006. While just four percent of employees with workplace-provided health insurance had high-deductible plans in 2006, that number was 20 percent by 2014 and 24 percent in 2015.

And it is that growing segment of the private-insurance market that is most feeling the EpiPen pinch of late—and saying "ouch!" PUBLIC RESPONSE

August 2016 was not a good month for Mylan—at least not PR-wise.

The end of the month featured numerous national headlines reporting several public setbacks resulting from the company's latest EpiPen price hike.

Sen. Amy Klobuchar of Minnesota, who actually co-sponsored the school EpiPen bill President Obama signed in 2013, released a statement reading, in part, that "This outrageous increase in the price of EpiPens is occurring at the same time that Mylan Pharmaceutical is exploiting a monopoly market advantage that has fallen into its lap."

Sen. Klobuchar also called for an immediate lowering of EpiPen pricing, and an investigation by the Federal Trade Commission (FTC) within 90 days.

On August 24, American Medical Association (AMA) president Andrew W. Gurman, M.D. issued a scathing critique.

"With Americans across the country sending their children back to school this month, many parents and schools are encountering sticker shock over the cost of EpiPens," read his official statement. "With many parents required to buy two or more sets of EpiPens just to keep their children safe, the high cost of these devices may either keep them out of reach of people in need or force some families to choose between EpiPens and other essentials."

The next day, Anaphylaxis for Reel's longtime spokesperson officially severed her ties with Mylan.

August 25 also saw Mylan scrambling for a defensive stance, conceding that it hasn't been doing enough to help people afford the emergency medication.

It announced that it would raise the discount offer to \$300 off the price of an EpiPen pack and double the eligibility threshold of its patient assistance program to 400 percent of the federal poverty level. That means a family of four making up to \$97,200 would pay nothing out of pocket.

In the same announcement, though, Mylan partially blamed pharmacy benefit managers, insurers, wholesalers and pharmacies—saying that they are responsible for 55 percent of the \$608 current list price for an EpiPen two-pack that consumers would pay without any insurance or financial assistance

It's not clear what economic calculus Mylan used to arrive at that specific figure.

But what is clear is that, until something drastic changes, EpiPen will be dangerously out of reach for too many parents of children with severe allergy.



SEP. 2016 • ISSUE NO. 142 HAMASPIK GAZETTE

### **HAMASPIK NEWS**

# **New York Disability Supports Community** Readies for 'Care Coordination' Change

# Top OPWDD Advisor: Hamaspik "Well Positioned" for Transition, All-around Services

Under a federal rule first enacted in 2014, the New York State OPWDD and its non-profit partners are readying for a big change to how Medicaid Service Coordination (MSC) is provided.

The vital MSC service has been provid-

ed by the OPWDD via Hamaspik and community non-profit partners for decades. With MSC, Medicaid Service Coordinators (MSCs) help assigned beneficiaries navigate the many Medicaid-funded supports

As such, employees who work as MSCs are a fixture in state human-services bodies and non-profits everywhere. At Hamaspik, where devotion beyond the call of duty is par for the course, the agency's corps of for people with disabilities. MSCs in three counties has built a loyal community following of its own.

But with the rise of the conflict-free case management concept, the federal Centers for Medicare and Medicaid Services (CMS) has lain down a key change for state agencies and non-profits alike whose services include your friendly and helpful MSC.

As of September 30, 2015 (more on that deadline later), the 21 states that got funding from a federal grant called the Balancing Incentives Program (more on that later) are providing MSC services conflict-free.

In plain English, that means that your MSC now doesn't work for the same organization that provides you with any of your other disability support services.

Instead, you'll get so-called care coordination provided by a different organization.

The thinking is that having a care coordinator outside your support services organization is more objective towards your needs, fairer to all provider organizations, and more person-centered—in short, free of any conflicts that may put other interests above yours.

# **ROOTS OF CHANGE**

The shift to conflict-free case management is one of the several federal changes to disability public policy brought to bear by the Affordable Care Act (ACA).

Specifically, a section of the 2010 "ObamaCare" law gave teeth to the Supreme Court's 1998 Olmstead decision—which in turn gave teeth to the 1990 Americans with Disabilities Act (ADA).

Under Olmstead, it is a violation of the ADA to not provide people with disabilities with the most independent support settings. ObamaCare built on that by quietly including the Balancing Incentive Program, which funded state programs that ostensibly enhance independent support settings.

Among these is conflict-free case management.

According to the text of the conflict-free case management rule enacted by the federal government in 2014, "Conflicts can arise from incentives for either over- or under-utilization of services; subtle problems such as interest in retaining the individual as a client rather than promoting independence; or issues that focus on the convenience of the agent or service provider rather than being person-centered."

"Many of these conflicts of interest may not be conscious decisions on the part of individuals or entities responsible for the provisions of service," the rule also notes.

Among the required elements of conflict-free case management are for case managers to not be family members of the individual getting or applying for services (or to anyone financially responsible for the individual), monitoring and oversight, and firewalls within single entities responsible for providing both case management and service delivery.

The CMS and partner states now believe that much of any existing conflicts of interest will be successfully reduced or even eliminated now that states that participated in the Balancing Incentive Payment program have had each provider agency transition their in-house MSC services to outside, objective care coordination.

# THE LONG RUN

But 13 states are still in the game.

Of the 21 states that participated in the Balancing Incentive Program grant during its 2011-2015 run, 13-including New York—have perpetuated their participation well past its initial September 30, 2015 concluding date.

The Empire State, for its part, is currently laying the groundwork for its MSCs' eventual shift from in-house to coordinated care—particularly within the New York State Office for People With Developmental Disabilities (OPWDD), where MSCs remain

The OPWDD is one of nine state bodies affected by the federal push to care coordination, and responding with internal plans

Being quite early in the transition process as it is, the OPWDD is now only looking at several ideas for how the services now provided by MSCs would be moved over to

Among these is having care coordination provided by existing organizations called health homes-non-profit or even for-profit healthcare providers that care for patients not with the traditional feefor-service model but with a team-of-specialists approach that rewards caregivers for patient results.

Regardless of what structure or model ends up being adopted by the OPWDD, the roughly 600 non-profits across the state that employ approximately 2,500 MSCs need not worry for those MSC jobs just yet-the OPWDD's three-phase plan CONTINUED ON PAGE 13 >>



READY, SET, LUNCH: MICHAEL MASCARI AND HOSTS IN HAMASPIK'S CONFERENCE



MEETING OF MINDS: THE OPWDD TOP ADVISOR WITH HAMASPIK CHOICE EXEC. **DIRECTOR YOEL BERNATH** 



HAMASPIK CARES: WITH DOWNSTATE REGIONAL DIR. MORDECHAI WOLHENDLER (L) AND EXEC. DIRECTO ASHER KATZ (C), MR. MASCARI OBSERVES HAMASPIKCARE'S FRONT-DESK HUB

E6 HAMASPIK GAZETTE SEP. 2016 • ISSUE NO. 142

# The Autism Update

# News and developments from the world of research and advocacy

# MYRTLE BEACH AIRPORT OPENS NATION'S FIRST AUTISM "QUIET ROOM"

The "Quiet Room" space for young travelers with autism, a national first for airports, officially opened at the Myrtle Beach Airport in South Carolina on Tuesday, August 23.

The opening was marked with a formal ribbon-cutting attended by Congressman Tom Rice; Horry County Council Members Mark Lazarus and Tyler Servant; Brad Dean, CEO of the Myrtle Beach Area Chamber of Commerce CEO Brad Dean; and Horry County Airport Administration officials

Myrtle Beach Airport's Quiet Room was conceived by the South Carolina-based Champion Autism Network, an advocacy group founded by autism mom and activist Becky Large.

Family air travel with children who have autism is notoriously challenging, with the unpredictable sights, sounds and enclosed spaces of busy airports and aircraft interiors typically highly overwhelming to sensory-sensitive young people with the developmental disorder.

The air travel industry has shown increasing sensitivity in recent years, though. "Our members have a number of programs to assist passengers with special needs," says Jean Medina, a spokesperson for trade group Airlines for America.

In September of 2013, for example, commercial carrier JetBlue launched its five-part Blue Horizons for Autism program to families of children with autism. That program was designed to acclimate young travelers to check-in, security screening, boarding, take-off preparation, and deplaning.

The first leg of Blue Horizons, a simulated pre-take off routine, had 300 youngsters with autism and their parents board an actual plane and taxi about the airfield for some 20 minutes

The MYR Quiet Room had actually opened to the public before the ribbon-cutting.

In the interim, Delta Airlines opened the second-such U.S. airport-based facility, a "Sensory Room" at Atlanta's Hartsfield-Jackson Airport.

Myrtle Beach Airport is five miles north of Surfside Beach, South Carolina, which in January of this year declared itself the nation's first "autism friendly travel destination" at the behest of the Champion Autism Network—offering a number of "kid-proof" hotels and beach cabin rentals, and beach-area businesses that have been trained to accommodate children who have autism.

# NEW APARTMENT COMPLEX BEING BUILT FROM GROUND UP AROUND AUTISM INCLUSION

Heidelberg, Pennsylvania will soon become the home of the country's second-ever

apartment complex built with autism integration in mind, according to a recent report in the *Pittsburgh Post-Gazette*.

The August 9 article quoted Elliot Frank, president and founder of the Pittsburgh-based Autism Housing Development Corp, as saying that the only other such apartment project in the entire U.S. exists in Richmond, Virginia.

"Most housing for people with autism is just for people with autism," Frank told the Post-Gazette. "Inclusiveness is what makes this different."

Frank explained that when educational and social services stop at age 21, many people with autism "graduate to the couch," with most living at home with their parents. Frank founded the autism housing group in

2011 to develop safe and affordable housing for adults with autism.

As such, half of the 42 apartments now under construction are reserved for people on the autism spectrum, with the other half open to the typical population.

All are for people with low- to moderate incomes, with monthly rents of \$565 to \$795. They are all also wheelchair-accessible, with six also fully meeting all Americans with Disabilities Act (ADA) disability construction standards.

The building also has a community room, a "quiet lounge," an exercise area and an office for staff from NHS. That non-profit, which provides education and human services for people with special needs, will be on site 25-40 hours per week to help ten-

ants, including linking them to social opportunities, financial counseling and medical services.

A Port Authority bus stops at the apartments, and grocery stores and other shops are within walking distance.

More housing for people diagnosed on the autism spectrum is planned. Frank told the newspaper that said his organization is "exploring a couple of opportunities with other groups."

The Dave Wright Apartments complex is a joint project of Autism Housing and ACTION-Housing, a Pittsburgh-based disability social-justice non-profit founded in 1957. Construction is scheduled to end before Sept. 15, the designated tenant move-in date.



● ► HAMASPIK NEWS

# Families' Robust Advocacy Secures State Approval of Two New Homes for Eight Sons

Nod Reflects OPWDD Responsiveness, Sensitivity to Pressing Community Living Needs

A single European marketing authority is beneficial, in his opinion, for both his industry and the country's National Health System (NHS).

According to Mr. Smith, the EMA helps reduce complexity and cost for drugmakers. "The UK generic and biosimilar medicines industry," he said in a statement, "urges the government to do everything possible to maintain this European marketing authorization system in the forthcoming negotiations with the European Union."

Other concerns raised by industry ex-

perts include whether British health and pharma companies will have to add British patents and trademarks to their existing EU patents and trademarks—or even whether such companies may lose their patent and trademark protections before they can obtain British patent and trade

Responding attentively and positively to sustained, robust grassroots advocacy by a number of New York families affected by disability, the New York State Office for People With Developmental Disabilities (OPWDD) recently approved two new group homes to residentially support those families' loved

The two new IRAs, for four designated and pre-approved residents each, will house those individuals with disabilities whose families had extensively petitioned the OP-WDD in recent months to provide their loved ones with residential supports.

Both IRAs will be built in Orange County and operated by Hamaspik of Orange County. One is designated for four adults and the other for four youths.

The community-centric Individualized

Residential Alternative (IRA) has been the OPWDD's primary housing model since the early 1990s, furthering the state agency's decades-long shift away from institutions that actually began in 1974.

In 2011, with institutionalization largely a thing of the past and the majority of New Yorkers with disabilities living in neighborhood IRAs all over the state, the OPWDD announced that it would be closing all its remaining institutions—now called Developmental Centers—by 2017. (The OPWDD's decision to eventually convert all existing Intermediate Care Facility (ICF) group homes to IRAs was also announced at the time.)

The green-lighting of not one but two IRAs reflects the OPWDD's push for ever-greater mainstreaming, an ear keen to community concerns, and an encouraging response to parental advocacy—not to mention a mutually trusting relationship between the state agency and the community non-profit built and reinforced over years of successful services delivery.

# Highest Users of State Mental-health Services Getting Far-reaching New HARP Program

# Hamaspik of Rockland Among Hudson Valley Providers of Program's Support Services

CONTINUED FROM PAGE 01

who've most used Medicaid mental-health services in the recent past.

Among other goals, HARP is designed to provide the critical social and emotional needs in patients' lives that make it far easier for them attain and retain good long-term mental health—healthy-life staples like social skills, jobs, ongoing support and more.

The program's first pilot efforts launched in New York City in April 2015. By October of that year, HARP programs, which service adults age 21 and up, were rolling out across the state.

The HARP program is not for everyone with mental illness. Neither is it exactly a new Hamaspik program.

As a matter of fact, it's quite the opposite—it's only for those New Yorkers whose Medicaid records indicate that they are the highest users of Medicaid-covered mental-health services.

Those individuals have been sent letters from the state DOH stating they have been selected to benefit from the new state HARP program. The HARP program is for those letter-holders only.

To benefit from HARP, the selected individual must first choose a regional health home, a specialized healthcare provider, from a list of approved health homes included in the letter.

The health home conducts an extensive evaluation of the individual. It then creates a customized plan of treatment for the in-

dividual based on the 12 support services offered by HARP.

The individual is then provided a list of regional providers of those 12 support services—and depending on his or her customized plan of treatment, and the services offered by regional providers, he or she could get all of those services from one provider, or from two or even more.

# TREATING CAUSES, NOT SYMPTOMS

Whether intervening in the lives of people with bipolar disorder, depression, obsessive-compulsive disorder, schizophrenia or other mental-health diagnoses, the HARP program gives its participants the critical short-term supports and services that they need to stay episode-free after their last relapse.

Once they are stabilized, long-term supports for months or more are also provided.

Those supports, short- and long-term, are quite specific.

They include regular and frequent home visits by a licensed social worker in the early post-crisis days, to compassionately stay on top of the patient in his or her vulnerable "drying out" stage. Such visits critically help avoid another rehospitalization.

Said social worker will eventually guide the patient to take up regular mental-health therapy—also equally critical in tending to the personal emotional and social issues fueling their mental-health issues.

At the same time, HARP can provide

the family with the equally-critical support training—making the ongoing recovery of a beloved child and sibling a family project that proactively involves loving parents, brothers and sisters, too.

Practically speaking, that means that a trained worker comes to the house and coaches family members on what to say and do—and, more importantly, what not to say and do—to show understanding, sensitivity, care and love towards the young man or woman living with them as he or she painfully withdraws from a mental-health crisis or gets effective long-term mental-health treatment, including medication.

In short, that family support training teaches family members what their loved one is going through, and how to best be there for him or her—turning his or her recovery into a family and team effort.

A third and equally critical service and one that arguably is the defining breakthrough service that sets HARP apart from earlier services—is one that also, upon reflection, would seem to be the most practicable, most effective and most exciting.

The HARP program recruits people who've recovered from mental illness, then empowers them to help peers to recover from mental illness—giving them the unique and self-affirming opportunity to give to others the gift of life and hope that was given to them.

Under this HARP service, people who survived the pain of mental illness to achieve the stability of long-term recovery can now help others as only they can.

The HARP program provides them with training and certification, and then lets them share their common experience with those going through what they once went through, with an eye toward permanent long-term recovery.

Other services provided by HARP are one-on-one habilitation, in which the recovering patient gets a personal coach in learning (or relearning) basic self-care skills and healthy personal habits. The coach will also help around the house and remind the patient to take his or her medications.

For the limited number of individuals with chronic mental illness who are fortunate enough to be served by it, the HARP program intervenes effectively in ways that earlier programs did not. At the same time, a sizable number of people with chronic mental-health issues, many not high Medicaid users but no less at hospitalization risk, remain dependent on standard options.

# **ON THE FRONT LINES**

This past January, Hamaspik was approved by the New York State OMH to be a HARP regional services provider in both Rockland and Kings Counties.

Heading up Hamaspik's HARP efforts in Brooklyn is Hamaspik of Kings County's David Schatzkamer. At the same time, Hamaspik of Rockland's very own Mrs. Pearl Spira is readying for the upstate agency's October 1, 2016 date of official approval

CONTINUED ON PAGE 11 >>

E8 HAMASPIK GAZETTE SEP. 2016 • ISSUE NO. 142

# In the Know

# ALL ABOUT... PHOBIAS

Phobias are the numerous paralyzing and irrational fears of people, places, things or possibilities. They are often laughed at, especially considering some of the more unusual entries in a very long list of documented phobias. (One source lists some 541 phobias.) But for otherwise reasonable and functional individuals who suffer from them, phobias are no joke.

From *arachnophobia*, which is the fear of spiders and the most common phobia, to *zoophobia*, the fear of animals, phobias literally run the list from A to Z—and differentiate themselves from ordinary and even healthy fears in their power to disrupt healthy and normal daily life.

Here's a decidedly short rundown on the problem of phobias, and the solution.

### **DEFINITION**>>

According to the Mayo Clinic, a phobia is "overwhelming and unreasonable fear of an object or situation that poses little real danger but provokes anxiety and avoidance. Unlike the brief anxiety most people feel when they give a speech or take a test, a phobia is long lasting, causes intense physical and psychological reactions, and can affect your ability to function normally at work or in social settings."

There are three general categories of phobias: Specific phobias, social phobia and—in a category of its own—agoraphobia, or fear of open spaces.

# Specific phobias

The *specific phobia* is the largest category of phobia.

Specific phobias involve a long-term, illogical and overwhelming fear of a specific object or situation that's entirely out of proportion to the actual (if any) danger.

Common specific phobias are:

- Fear of situations, like enclosed spaces (claustrophobia) or airplanes (variously known as aerophobia, aviophobia, aviatophobia or even pteromerhanophobia)
- Fear of natural, environmental phenomena, such heights (acrophobia, altophobia or batophobia) or thunderstorms (which has several names including astraphobia, brontophobia, ceraunophobia or tonitrophobia)
- Fear of animals (zoophobia) or insects (entomophobia)
- Fear of blood (hemophobia), injection (trypanophobia) or injury (traumatophobia)
- Fear of loud noises (ligyrophobia) or clowns (coulrophobia, especially among kids)

# <u>Social phobia</u>

"Oh, don't be shy!" might work in ordinary situations.

But for a person with social phobia, the fear of public scrutiny or humiliation in common social situations, like attending a wedding or bris, triggers an overwhelming fear and self-consciousness that will typically keep the person home—out of fear of being rejected or negatively judged.

Fear of open spaces (agoraphobia)

In a league of its own, agoraphobia literally means "fear of open spaces" but more broadly refers to fear of actual or anticipated situations—like using public transportation, being in open or enclosed spaces, standing in line or being in a crowd, or being outside the home alone.

If a person with agoraphobia has a panic attack while in a specific space or situation—for example, a crowded bus or train—he or she might now fear being unable to control the situation should another panic attack strike on the bus, train or other specific space/situation. For some people, agoraphobia may be so severe that they literally cannot leave their homes.

### **SYMPTOMS**>>

Regardless of which of the three types the person has, phobias common produce the following symptoms:

- A feeling of uncontrollable panic, terror, dread or anxiety when exposed to the source of the fear—or sometimes by even thinking about the source of the fear
- The feeling that one must do everything possible to avoid what he or she fears
- The inability to function normally because of the fear
- Physical reactions like sweating, rapid heartbeat and difficulty breathing
- Knowing in the mind that the fear is unreasonable—but feeling powerless in the heart to control the fear

In children, phobias can present with any of the above, as well as possibly temper tantrums, clinging or crying.

### **CAUSES** >>

What precisely causes phobias is not completely known, but there seems to be a link between one's own phobias and those of his or her parents—indicating that genetics, learned behavior or some combination of both may be a cause.

### **DIAGNOSIS>>**

Phobias are diagnosed if the symptoms meet the definitions of phobia as defined by the Diagnostic and Statistical Manual (DSM), the authoritative "bible" of mental disorders. A diagnosis of phobia is made after a thorough visit with a mental-health professional like a psychiatrist, psychologist or social worker.

The mental-health professional will first ask the patient questions about symptoms and take a medical, psychiatric and social history.

The phobia diagnosis that follows, if any, depends on the DSM's definition of each type.

### Specific phobias

Diagnostic criteria for specific phobias include:

- An intense fear or anxiety triggered by an object or situation
- An immediate anxiety response when confronting the source of the fear



- Fear or anxiety that is irrational or out of proportion to the risk posed by the object or situation
- Avoidance of the object or situation fear, or enduring it with extreme distress
- Significant distress or problems with social activities, work or other areas of life due to the fear, anxiety and avoidance
- Persistent phobia and avoidance that usually lasts six months or more

# Social phobia

Diagnostic criteria for social phobia include:

- An intense fear or anxiety in one or more social situations where there is the possibility of scrutiny by others
- Fear of embarrassing or humiliating oneself, or getting viewed negatively/rejected by others
- Intense anxiety, which may take the form of a panic attack, that almost always results from exposure to social situations
- Avoidance of any such social or performance situations that are feared
- Fear entirely out of proportion to any real risk of being viewed negatively by others
- Problems or distress that severely affect life, including job, social activities and relationships
- Persistent phobia and avoidance that usually lasts six months or more

### **Agoraphobia**

Diagnostic criteria for agoraphobia include a severe fear or anxiety about two or more of the following situations:

- Using public transportation like buses, subways, planes or even cars
- Being in open spaces like parking lots, bridges or malls
- Being in enclosed spaces like social halls, conference rooms or small stores
- Waiting in a line or being in a crowd
- Being out of the home alone

These situations cause anxiety because the person fears that he or she won't be able to escape or find help if panic-like symptoms or other incapacitating or embarrassing

symptoms come on.

Diagnostic criteria for agoraphobia also include:

- Fear or anxiety that almost always results from exposure to the situation
- Avoidance of the situations, required assistance of a companion or endurance of situations with extreme distress
- Fear or anxiety that is out of proportion to the actual danger posed by the situations
- Significant distress or problems with social situations, work or other areas in life caused by the fear, anxiety or avoidance
- Persistent phobia and avoidance that usually lasts six months or more

### **TREATMENT** >>

To treat a phobia, a doctor or a mental health provider may suggest behavior therapy, medication or both. Unfortunately, phobias in adults usually do not get better on their own and will require some type of treatment.

The goal of phobia treatment is to reduce the anxiety and fear, and to help the patient better manage his or her reactions to the object or situation that causes them.

Treatment depends on the type of phobia one

- Specific phobias are usually treated with exposure therapy
- Social phobias are usually treated with exposure therapy (and/or with antidepressants or other medications if necessary)
- Agoraphobia, especially when accompanied by panic disorder, is usually treated with exposure therapy (and/or with antidepressants called SSRIs if necessary)

Cognitive behavioral therapy may also be part of any treatment plan for any type of phobia.

# **Exposure therapy**

For treating phobias, the form of psychotherapy (a.k.a. talk therapy) called exposure therapy is the most common and most effective treatment. Exposure therapy is also known as desensitization. Desensitization focuses on

transforming one's response to the object or situation fear from negative to neutral and ideally positive.

Gradual, repeated desensitization to the cause of the phobia has been show to help patients learn to conquer their anxieties.

For example, if a person is afraid of elevators, exposure therapy may progress from simply thinking about getting into an elevator, to looking at pictures of elevators, to going near an elevator, to stepping into an elevator.

Next, the patient may take a one-floor ride, then ride several floors and then ride in a crowded elevator.

### Cognitive behavioral therapy

Cognitive behavioral therapy is another, more complex and extensive form of talk therapy that may be used to treat phobias.

In the case of treating phobias, cognitive behavioral therapy combines exposure therapy with other techniques to teach the patient how to view and cope with the feared object or situation. In cognitive behavioral therapy, the patient learns alternative beliefs about his or her fears and the impact they have on his or her life. Cognitive behavioral therapy places special emphasis on learning to develop a sense of mastery and control of one's thoughts and feelings.

# **Medications**

Medications can help patients control the anxiety and panic that stems from thinking about or being exposed to the object or situation that triggers the phobia. Medications used as part of phobia treatment plans include:

• Beta blockers, which block the stimulating effects of adrenaline on the body that result in increased heart rate, elevated blood pressure, pounding heart, and shaking voice and limbs. Short-term use of beta blockers can be effective in decreasing symptoms when taken before an anticipated event, for example, before a performance for people who have severe stage fright.

- Antidepressants called selective serotonin reuptake inhibitors (SSRIs), which act on the chemical serotonin, a neurotransmitter in the brain that's believed to influence mood.
- Sedatives called benzodiazepines can help patients relax by reducing the amount of anxiety they feel. Sedatives need to be used with caution because they can be addictive.

### **Self-coping tools**

People recovering from phobias can also take any of the following steps on their own to cope and care for themselves:

- Try not to avoid feared situations. Family, friends and therapists can help with this.
- Reach out. Join a self-help or support group to connect with others who identify.
- Take care of yourself. Get enough rest, eat healthy and try to be physically active every day.

# Coping tools for children

Most children outgrow such common childhood fears like fear of the dark, "monsters," the closet or being left alone. However, a child with a persistent, excessive fear that hinders his or her ability to function in daily life should be professionally treated. In the meantime:

- Talk openly about his or her fears. Don't dismiss the problem or belittle the child for being afraid. Instead, let him or her know that Tatty and Mommy are there to listen and to help.
- Don't reinforce phobias. Instead, take advantage of opportunities to help children overcome their fears—instead of going out of the way to avoid your child's specific fear, help him or her cope when confronted by the fear by slowly stepping closer to it each time you pass it.
- Model positive behavior. Because children learn by watching, demonstrate how to respond when confronted by something your child fears; first demonstrate fear and then show how to overcome it.

# **PROGNOSIS**>>

Despite the looming, terrifying and all-consuming nature of phobias, the repeated and therapeutic acclimation that is exposure therapy is known to work and work well—allowing people to confront and evaporate the paper tiger that is phobias, along with medication should that be needed, too, and to gain the fuller, richer life they thought they could never have.

# The Ten Most Common Phobias

Rank	Name	Definition	Fast fact
1	Arachnophobia	Fear of spiders	Affects four times more women than men
2	Ophidiophobia	Fear of snakes	Some even avoid certain cities because they have more snakes
3	Acrophobia	Fear of heights	Five percent of the general population has this phobia
4	Agoraphobia	Fear of open spaces	People with this fear often won't leave home
5	Cynophobia	Fear of dogs	Terrified of poodles? You're not barking mad
6.	Astraphobia	Fear of thunder/lightning	Has several other names
7	Claustrophobia	Fear of small spaces	Probably the most commonly known phobia
8	Mysophobia	Fear of germs	Also rightly termed germophobia
9	Aerophobia	Fear of flying	Up to 25 million Americans have this phobia
10	Trypophobia	Fear of holes	This phobia is actually fairly common



HAMASPIK
24 HOUR
EMERGENCY
HOTLINE

**877.928.9000** 

E10 HAMASPIK GAZETTE SEP. 2016 • ISSUE NO. 142

# THERANOS CEO FACES CRITICS, PRESENTS NEW PRODUCT

At the annual meeting of the American Association for Clinical Chemistry, which saw some 2,650 scientists converge on Philadelphia this past August 1, embattled Theranos CEO Elizabeth Holmes took on critics and questions. Ms. Holmes' finger-prick blood-test technology com-

pany suffered huge setbacks in recent months after federal authorities raided several Theranos labs

> and the company lost a huge business deal with national pharmacy chain

> > Walgreens. According to Holmes, Theranos is working on a new desktop "minilab" product, and working to clean up its laboratory services

JUMPING TRAMPOLINE PARKS, JUMPING KIDS' INJURIES

A study published Aug.

1 in *Pediatrics* finds that while children's injuries due to home trampolines have remained level, children's injuries incurred at trampoline parks have jumped. The number of the ever-popular trampoline parks has dramatically jumped in recent years.

According to the study's research, there were 280 trampoline parks worldwide by 2014, compared to 35 in 2011. The study correlates the increasing injuries with the increasing parks.

Specifically, researchers found 580 records for U.S. emergency-room incidents involving trampoline parks in 2010, but nearly 7,000 for 2014.

Most of those injured were children and teens, and most injuries consisted of broken bones and rains. A handful of injuries were more severe.

Researchers and experts say that trampoline-park injuries are best prevented by grouping kids by age/height, preventing crowding, and banning flips or other high-flying stunts.

# NEW YORK MEDICAL SCHOOLS NO LONGER AGAINST 'DIGNITY BILL'

New York State has 16 medical schools, with eight of them in New York City alone. And until recently, most of them opposed a bill that would bar them from misusing unclaimed bodies for "research" and "education" without explicit family member consent. Under the bill, now only need-

ing Gov. Cuomo's immediate signature, medical schools will first need to exhaustively search for any living relatives of the deceased before engaging in the dubious practice. In a win for the dignity of the nameless deceased, though, the schools have now dropped their opposition.

### JANUARY VERDICT FOR AET-NA-HUMANA MEGA-MERGER

In December 2016, a federal judge is set to hear the looming antitrust challenge against Aetna and Humana's proposed \$37 billion merger, with the decision scheduled for mid-January 2017. The schedule was announced on Aug. 10 by the U.S. District Court for the District of Columbia, the Hon. U.S. District Judge John Bates presiding.

# FOR RICHER, HIGHER CARE COST—AND QUALITY

A recent report in *Health Affairs* builds on the decade-plus trend in slowing health-care costs. According to the report, the cost of care has actually been shrinking since 2004 for the lowest of five income classes. But the report also found that the average annual healthcare costs for the middle class held relatively steady during that time—while the highest class continues to see rapidly rising costs.

The researchers write that the findings "could represent a shift from need-based to income-based receipt of medical care," fearing that they "might presage deepening disparities in health outcomes."

# DESPITE 'VISION ZERO,' NYC CYCLIST DEATHS UP

The loss of healthy 78-year-old Michael Schenkman of Queens this August 24 marked New York City's 16th cyclist fatality due to auto accident in 2016. Riders using a record number of bike lanes across the city's five boroughs still keep clashing with motor vehicles, despite Mayor Bill de Blasio's Vision Zero long-term speed- and accident-reduction plan.

# CITY SETS PRIMARY-CARE CHANGE GOAL

The Big Apple's healthcare leaders rolled out an ambitious goal in August: to have 80 percent of the city's primary care practices adopt the medical home care model by year 2020. In contrast to traditional doctors' offices, the medical home model centers on team-based care. There are nearly 10,200 primary care providers in New York City today, with about 25 percent currently recognized as medical homes.

# NEW YORK SILVER PLANS JUMP IN 2017

For Year 2017, monthly premiums for

the lowest-cost ObamaCare Silver individual plan sold in New York City will rise 22.9 percent, according to rates newly released by the state Department of Financial Services. The rest of the state won't fare much better, with the average increase for a Silver plan being 16.6 percent. However, over half of individuals who enroll qualify for tax credits that reduce final cost; the new enrollment period begins Nov. 1 and runs through Jan. 31, 2017.

# FEDS AWARD \$53 MILLION TO FIGHT OPIOID EPIDEMIC

On August 30, the Obama administration announced \$53 million in grants to help states fight the opioid abuse epidemic while also calling on Congress to allocate another \$1.1 billion toward the effort, Med-Page Today reported.

"These grants we're announcing today are an important step forward, and we hope Congress will take the next step," U.S. Dept. of Health and Human Services (HHS) Secretary Sylvia Burwell said on a conference call with reporters.

# STUDY: WHY DO MEDICATIONS COST SO MUCH?

High prescription drug prices are attributable to several causes, including the approach the U.S. has taken to granting government-protected monopolies to drug manufacturers, and the restriction of price negotiation at a level not observed in other industrialized nations, according to a study appearing in a recent edition of the *Journal of the American Medical Association (JAMA)*.

The increasing cost of prescription drugs in the United States has become a source of growing concern for patients, prescribers, payers, and policy makers. In the United States, prescription medications now comprise an estimated 17 percent of overall personal health care services.

According to the study, drug prices are higher in the United States than in the rest of the industrialized world because the U.S. health care system allows manufacturers to set their own price for a given product.

# HILLARY CLINTON RELEASES MENTAL-HEALTH AGENDA

The presidential campaign of Democratic candidate Hillary Clinton released a plan on August 29 to tackle gaps in the country's mental health system, once again using President Barack Obama's health care law as a starting point for further reforms. Like Obamacare, Clinton's plan aims to put mental health on the same level as physical health care in terms of how it is paid for by insurance companies.

# **MR. PRECEDENT**

In a first for a sitting American chief ex-

ecutive, an academic paper, "United States Health Care Reform: Progress to Date and Next Steps," was published this past August in the prestigious Journal of the American Medical Association (JAMA).

Its author? One B. Obama, J.D., a Harvard Law School graduate and Chicago social-justice advocate who is also current President of the United States of America.

Though not peer reviewed, the paper was in fact fact-checked for two months before its publication.

# FDA OKS CONCUSSION SCREENING APP

In late August, the U.S. Food and Drug Administration (FDA) approved the Im-PACT software and medical app, designed to help clinicians test a patient's cognitive skills after a head injury.

In recent years, a number of medical apps were rolled out to help clinicians assess for concussions at the point of care, like NYU Langone Medical Center's Concussion Tracker ResearchKit.

Langone's app also better characterizes symptom evaluation after a concussion—which is critical to designing other medical apps aimed at diagnosing concussions

The Immediate Post-Concussion Assessment and Cognitive Testing (ImPACT) app has two versions. The first is designed for patients between 12 to 59 years old and runs on a laptop. The other, ImPACT Pediatric, is for kids younger than 12 years old and runs on an iPad.

Tests take about 25 minutes and re-

sults can be compared to an age-matched cohort from the company's large database of "normal" patients or to pre-injury baseline test taken by the patient.

But, as the FDA points out in its press release, ImPACT is not designed to diagnose a concussion or recommend treatment

Concussions and other head injuries, particularly related to sports, have garnered a lot of attention in recent years.

# IS ANTI-VAX MOVEMENT GROWING?

If childhood vaccination causes autism, it would grimly then follow that all (or most) vaccinated children should have autism, right? And, conversely, children who do not get vaccinated should have less rates of autism, right?

Wrong, and wrong.

Contrary to the fringe "anti-vax" movement, largely built on the discredited notion that the measles-mumps-rubella (MMR) vaccine given commonly to kids causes autism, kids who get vaccinated do not develop autism as a result. And at least one study of deliberately non-vaccinated children found not only equal-to-the-mainstream but higher rates among them of autism. (So much for that theory.)

Still, a recent survey of pediatricians indicates that the anti-vax movement is making a creeping rebound of late—but with parents primarily refusing this time for lack of belief of efficacy, not fear of direct harm.

● ► HAMASPIK NEWS

# Highest Users of State Mental-health Services Getting Far-reaching New HARP Program

HAMASPIK OF ROCKLAND AMONG HUDSON VALLEY PROVIDERS OF PROGRAM'S SUPPORT SERVICES

CONTINUED FROM PAGE 7

for operations.

For the past two months, Mrs. Spira—as Hamaspik of Rockland County's lead on all things HARP—attended extensive state-provided training sessions to lay the groundwork for the agency's latest community-oriented program.

For people in the Hudson Valley who've received HARP program notification let-

ters, then, Hamaspik of Rockland County now stands by available to provide five of HARP's 12 services.

With HARP, Hamaspik furthers its commanding position as a communal resource for a growing number of social services and supports.

If you've received a HARP participation letter for Rockland County, please call Kathleen Clay of Hudson River Healthcare at 914-734-8513 or Noel Sander of Hudson Valley Care Coalition at 914-502-1435. For any questions on Hamaspik of Rockland County support services for HARP beneficiaries, please contact Mrs. Pearl Spira, LMSW at 845-503-0247.

# TOD Opportunities

# 61ST STREET BRIDERHEIM (HAMASPIK of KINGS)

Is looking for a **Assistant Residence Manager** and for **Day Staff**, Hours are: Sun – Friday 7am-9am and Sun – Thursday 3pm-8pm.

Please email your resume to: cfisher@hamaspikkings.org

# 38TH STREET SHVESTERHEIM (HAMASPIK of KINGS)

Is looking for **Day Staff**, Hours are: Sunday 9am-7pm, Mon-Fri 9am-7am, Mon-Thurs 3pm-8pm.

Nice pay with full benefits. DSP, Driver's License required.

There is also an **Open position for a Shabbos Couple.**Please reply to ykasnett@hamaspikking.org or fax 718-943-9236.

# HOME CARE SCHEDULING COORDINATOR (HAMASPIK of KINGS)

Description: Coordinate/schedule home attendants for homebound patients. **Must have phone skills**, be **computer savvy**, and **read/write English and Yiddish**. Knowledge of a **third language a plus**.

Location: Boro Park - Brooklyn, NY

Required Experience: Basic office experience

Required Degree: None

Benefits: **Health Insurance** - holiday and vacation pay.

Hours: M-T 9-5 F 9-1

Language: Bi-lingual English/Yiddish

To apply send resume to:

F: 718-408-7706

E: Hamaspik@outlook.com

# COMMHAB OPPORTUNITIES (HAMASPIK of ROCKLAND)

Looking for someone who can take a **high functioning 19 year old man with special needs to shul** on Friday night and Shaalos suedos. **Will pay.** (Chestnut Ridge) Please call 845-503-0214.

Looking for a female to work with a **special needs young lady part-time. Must Drive**. Hours are flexible in some afternoons or early evenings. Excellent pay! (pay is not through an agency).

Please call: 845-641-3940 or: 845-503-0242

# AFTER SCHOOL PROGAM (HAMASPIK of ROCKLAND)

Now Hiring For The Coming School Year. Starting September 6th. **A rewarding and fun-filled experience.** For high school and post-high school girls. **Good Pay.** If interested, please fax resume to 845-425-7983, or call 845-425-3421 and leave a detail message.

E12 HAMASPIK GAZETTE SEP. 2016 • ISSUE NO. 142



# PHILIPS SELLING NEWEST HEALTH GADGETS

On August 1, Dutch electronics giant Philips started selling its four newest retail health gadgets. Besides the \$250 Health Watch, which monitors wearers' all-day activity, sleep and heart rates, consumers can also buy a smart" Internet-connected body analysis scale for \$100, a data-sharing ear thermometer for \$60, and connected blood-pressure monitor for the upper arm (\$100) or wrist (\$90).

# DRUG REDUCES CHEMO DAZE FOR DAYS

The "C disease" is dreaded not just because of its grim reputation but also because of the terrible nausea caused by one of its most effective treatments, chemotherapy. Up to 80 percent of patients treated with chemotherapy experience that debilitating side effect, and it remains the leading reason for discontinuing chemo treatment.

But chemo patients may now have a new option with Sustol, a drug approved August 10 by the FDA.

While a handful of medications do exist to reduce chemo-induced nausea, none boast benefits as long-lasting as Sustol, according to maker Heron Therapeutics. Other chemotherapy-induced nausea and vomiting (CINV) drugs like Aloxi are generally effective for 48 hours or less, while Sustol can protect patients for up five days, the company said.

However, the FDA only approved Sustol in combination with other CINV preventatives—and excluding those that are platinum-based.

# YUP, EXERCISE IS GOOD FOR YOU...

Yet another study has concluded that exercise is good for you. This one, actually a study of 174 others studies between 1980 and 2016, found a correlation between higher levels of weekly physical activity and lower risks of diabetes, heart disease and stroke, among other things.

The study, published Aug. 9 in the journal BMJ, found that what seemed most beneficial was the weaving of physical activity into daily routines, like ten minutes of climbing stairs, 15 minutes of vacuuming, or 20 minutes of gardening.

# ANOTHER MUSICIAN BLOWS HYGIENE

This time it was a proper British bagpiper, and it ended tragically.

But recent articles in *USA Today* and other outlets reported the death of a 61-year-old Liverpool man due to his bagpipes, which he played regularly—and whose moist, dark interior hosted a flourishing fungus colony that gave the unfortunate man the lung condition that did him in.

The condition, hypersensitivity pneumonitis, is caused by inflammation and scarring of the lungs caused by the immune system fighting off invaders. In the man's case of "bagpipe lung," those invaders were the mold and yeast growing in his regularly uncleaned bagpipes.

It's not the first time a horn or wind instrument made a musician really sick. British bagpiper John Shone came close to losing his life from "bagpipe lung" three years ago. And the Nov. 2010 *Gazette* reported on Scott Bean of Connecticut, whose 15 years of onand-off symptoms were attributed to the fusarium mold flourishing in his trombone—which, once thoroughly cleaned, also gave him a clean bill of health.

# **FLU'S IN THE NEWS**

Regardless of the fact that it's around this time of the year that national health authorities select the three strains of flu virus to be included in the coming year's vaccine, flu's in the news again.

A McMaster University study finds that last year's nasal spray and needle injection versions of the flu vaccine produced equal levels of community immunity against the flu virus.

According to the study, conducted on Hutterite religious communities in rural Canada, community members who had gotten the standard flu vaccine by needle injection were found to have a 5.2 percent rate

of flu occurrence (meaning, 94.8 percent flu-free)—while those community members who had gotten the standard flu vaccine by FluMist nasal spray were found to have a 5.3 percent rate of flu occurrence (meaning, 94.7 percent flu-free).

The strength of the three-strain FluMist is significant because a CDC advisory committee had previously voted against recommending the updated four-strain FluMist for children in the upcoming 2016-2017 flu season

But that vote was largely influenced by the fact that in the last three flu seasons, the annual vaccines, especially the nasal-spray vaccines, offered little to no protection against the dominant H1N1 and H3N2 flu strains.

# NOVARTIS WORKING ON ASTHMA

A pill-based medication called fevipiprant is under development by giant drugmaker Novatis. The medication, which just completed a clinical trial at the University of Leicester (England), would ostensibly help people with asthma simply take a pill to treat and control their asthma.

People with the common respiratory disorder typically use spray-based inhalers to open up the constricted airways that are a primary symptom of asthma.

In the study, 61 participants with asthma were given fevipiprant or a placebo. After 12 weeks, the study found that participants on fevipiprant had much lower levels not of asthma symptoms but of certain white blood cell markers that are associated with asthma symptoms.

Bigger and longer studies are needed to test fevipiprant's long-term safety; meanwhile, the drug is years away from the market and, contrary to some publicity, is not the first asthma pill in 20 years—several tablet-based asthma drugs called *leukotriene receptor antagonists* already exist.

# **HAND IT TO HIM FOR SPUNK!**

We can all learn a thing or two from the optimism and hope of little kids, untarnished as they are by the burdens of life as us working adults. That's certainly the case for a nine-year-old Baltimore, Maryland boy who last year became the first child to receive a double hand transplant. The lad lost his hands and feet at age two to a life-threatening infection.

After an 11-hour surgery last summer, the boy has been following a rigorous therapy regimen, and is now able to freely use his new hands to throw, catch, write and do all the things that bouncy little boys do—including tossing out the first ball at a recent baseball game.

In response to a reporter asking for his favorite thing about his new hands, the budding young man said, "Just being able to wrap them around my mom."

Thumbs up to the best response ever—hands down!

### THE SCIENCE OF CUTENESS

Ouick! Define "cute"!

"Well," you might say, "everyone knows what 'cute' is!" But it turns out that cute is rather scientific, according to a fascinating recent review of the subject in a Washington Post column.

That scientific knowledge helps power a multi-billion-dollar industry that sells children's products, as well as photos of positively scrumptious babies and irresistibly adorable little animals.

According to a body of academic research, the science of cuteness begins the large eyes and heads, button noses, soft, chubby bodies, floppy little limbs and teetering gait of babies.

Decades ago, Nobel-winning Austrian zoologist Konrad Lorenz, often considered the father of cuteness research, studied the bonding process between baby animals and caregivers. Lorenz held that large eyes, bulbous foreheads and small chins trigger parental caretaking behavior.

These traits are signals to parents that a baby is healthy and worth caring for, according to some researchers.

Nowadays, studies have shown that pictures of cute babies cause the brain to release dopamine, the same chemical that is released when people bond strongly with others.

Other research has shown that cuter babies get better care from their parents, and that cute kids are more likely to be engaged in friendships and play.

Manufacturers have also long been capitalizing on cute, making products rounder, and giving them softer edges and larger "eyes." A 2011 study along these lines actually found that consumers see car fronts like human faces and headlights like eyes—eliciting more positive reactions from cars with big, round headlights.

Cuteness is an especially powerful force in our world because it is something that can be consumed in quick, small doses. And it has blossomed in our consumerist culture because it is incredibly good at selling things.



HAMASPIK CENTRAL INTAKE FREE 866.353.8400

ORANGE COUNTY **845.774.0300** 

ROCKLAND COUNTY **845.503.0200** 

KINGS COUNTY 718.431.8400

### ● ► HAMASPIK NEWS

# New York Disability Supports Community Readies for 'Care Coordination' Change

# Top OPWDD Advisor: Hamaspik "Well Positioned" for Transition, All-around Services

**CONTINUED FROM PAGE 5** 

to switch to care coordination will only be first implemented in 2018, according to the agency's current transition schedule.

### **ON THE FRONT LINES**

With all those sweeping changes looming in the background, Hamaspik was honored to host Michael "Mike" Mascari at an official visit this past August 8. Mr. Mascari was recently recruited as Senior Advisor to OPWDD Acting Commissioner Kerry A. Delaney after decades of disability non-profit leadership.

The visit opened with a comprehensive guided personal tour of Hamaspik's Rockland County hub. The sprawling nerve center is also headquarters to the successful and growing HamaspikCare home-care agency and Hamaspik Choice managed long term care (MLTC) program.

Mr. Mascari spent close to an hour meeting and chatting with those entities' dozens of employees, garnering first-hand familiarity with Hamaspik's multifaceted human-services programs, and the faces and names behind them.

"Everyone has more than one job!" he affably noted at one point, as he and his entourage were shown about the offices.

Talking with the professionals manning desks and directing departments across the complex, the OPWDD leader came away impressed by the employees' command of their job duties.

In particular, Mascari was impressed with a brief discussion on present growth and future plans with Yoel Bernath, the seasoned industry veteran currently serving as Executive Director of Hamaspik Choice.

# **GETTING TO KNOW YOU**

At a working business luncheon with agency leadership that followed, nearly two dozen Hamaspik top brass formally introduced themselves and their departments or divisions to the guest of the hour.

Of Hamaspik of Rockland County, those were: Executive Director and agency founder Meyer Wertheimer, Quality Assurance Director Eliezer "Lazer" Appel, Com Hab and Early Intervention (EI) Program Director Eliezer Eizikovits, Development Coordinator Zalman Stein and Public Relations Director Pinchus Weinstock.

Also present from Hamaspik of Rockland were Comptroller Solomon Wertheimer, Director of Day Services Shloime Kornbluh, Residential Services Director Moshe Sabel, longtime MSC Supervisor (and self-described "Hamaspik tour guide") Nechama Nissenbaum, RN, veteran Intake Coordinator Mrs. Rachel Tress, and NHTD/ TBI Director Tzivi Frommer, LMSW.

Representing Hamaspik of Orange County was: Executive Director Moses Wertheimer, Director of Residential Services Joel Weiser and Quality Improvement Coordinator Joel Gross.

Joel Freund, Executive Director of Hamaspik of Kings County and Director of the New York State Hamaspik Association (NYSHA), introduced himself and his operations next.

Rounding out the introductions around the tables were Asher Katz and Mordechai "Mordy" Wolhendler, respectively the Director and Downstate Regional Director of HamaspikCare. Last but not least were Chaya Back, RN, Hamaspik Choice's energetic Clinical Director, and 14-year Hamaspik veteran Raizy Mermelstein, Hamaspik Choice's Intake and Enrollment Coordinator.

As lunch was served and conversation turned informal, a short, catchy video overview of Hamaspik was shown.

"I think it captures the spirit of the organization," Mr. Mascari said.

# APPRECIATION FOR SHARED MISSION

Hamaspik of Orange County's Moses Wertheimer opened the luncheon's working discussion with a heartfelt message of thanks from Hamaspik to Acting Commissioner Delaney and the entire OPWDD for the recent approval of two new IRA residences for individuals in desperate need.

Those individuals, all of whom have been in "the system" for years, have "tremendous" challenges, Mr. Wertheimer elaborated. "It's very difficult for the parents, for the family, to have the individuals at home," he said, "and they keep on begging, "What can you do for us?"

"We can go along with whatever's available," he continued. "But this direction that you took, approving us [for] two new homes, shows that with the effort, the willingness, to do that, it is available to do so, and we appreciate all the effort that you did. We thank you for that."

A strong and genuine round of applause ensued.

A prolonged dialogue between Mr. Mascari and Hamaspik leaders followed, with burning issues like the need for more community group homes, the Family Care program and so-called self-directed services discussed at length.

The lead OPWDD advisor expressed

support for an ongoing grassroots push for more residential housing as recently exemplified by Hamaspik's beneficiary community.

"You've got to be able to bring the reality to the people in government; they need to know that... there are individual people with names behind them that have needs," he said. "And I think you did a good job of translating a policy into the concrete reality of who these families are."

Responding to Meyer Wertheimer making the case for enhanced Family Care supports, Mascari praised Hamaspik for sticking with the program—matching the often-uncompensated personal dedication of Family Care providers with compassion of its own. "You have done everything probably beyond what most agencies do," he said. "It's going to take agencies that really go the extra mile and continue to do that as opposed to agencies that are struggling just to survive."

Various ideas for supporting or even expanding the Family Care program were mentioned as the conversation proceeded, like combining it with the popular home-care programs offered via numerous non-profits by the New York State Dept. of Health (DOH).

Mr. Mascari urged Hamaspik to craft new solutions to the housing and Family Care problems.

# **LEADING INTO THE FUTURE**

The high-ranking OPWDD guest next engaged his hosts in a dialogue on a loom-

ing issue at hand—that of the impending transition of MSC to conflict-free care coordination.

The issue is two-pronged, according to Mr. Mascari—with one being compliance with "conflict-free" itself, and the other how the sea change will affect existing provider organizations like Hamaspik, as well as the numerous MSC provider organizations in each region.

The state's current plans are to divide the state into a handful of regions, with one or two designated conflict-free care coordination entities serving each region come 2018.

"That's where it's going in the next five years," Mascari pointed out. "I think you're well positioned to be at the forefront of that change."

A brief discussion followed on the future of the Individualized Residential Alternative (IRA) and Intermediate Care Facility (ICF) group home models, as well as NYSHA's Article 16 Clinic.

The meeting then began wrapping up.

"I appreciate all the time and thought that went into this agenda here. I leave not only with a better understanding of the work that you're doing here, but some of the discussion here," Hamaspik's guest offered—"some thoughts that I might talk to the Commissioner about, in addition to the recommendations that you brought up already."

He concluded by saying, "I think your organization's going to be one that will continue to be a leader."

# ● ► PUBLIC POLICY NEWS

# The Washington Senator, the FDA Head, the Data Silo and the Heartbeat Wristwatch

CONTINUED FROM PAGE 3 shift."

The two editorials come against the background of a public health policy study written by the highest-ranking public official in the country, and world, for that matter, U.S. President Barack Obama, who took to the prestigious pages of the *Journal of the American Medical Association (JAMA)* on Aug. 2 to make a compelling case for the efficacy of his Affordable Care Act.

But personal health data finds itself increasingly at loggerheads with personal privacy—with the powerful provisions of the

landmark HIPAA patient-privacy law long since outmoded by the advent of personal health-data technology.

Those newfangled wristwatches that count your every footfall and take your pulse, ever-efficient and increasingly-shrinking blood glucose monitors, and smartphone apps that keep an eagle eye on your diet and exercise habits (if you're honest, that is) are all an infinite treasure trove of data just waiting to be mined.

But who gets their hands on that data, and what they do with it, remains to be seen



# Happening In Hospitals Today

# INDUSTRY SURVEY: HACKINGS HAVE HOSPITAL IT HEADS HAS-SLED, BUT MANY STILL DON'T ENCRYPT

With wholesale hospital patient data heists in the news in recent months and years, the hospital information technology (IT) security community has been increasingly on guard.

However, according to a recent survey conducted by the Healthcare Information and Management Systems Society (HIMSS), a health IT industry trade group, a significant minority of hospital IT heads still do not encrypt their patient data systems.

For hospital employees whose task it is to secure all sensitive patient information, Public Enemy No. 1 are the "ransomware" attacks in which cyber criminals hack into hospital databases and hold it hostage until a ransom is paid, according to the survey.

Most survey respondents also believe that the hackers' primary motivation is to commit medical identity theft—a category of identity theft that uses key patient information to obtain for healthcare uner that patient's name.

Medical identity theft is particularly harmful in today's interconnected world of electronic health records (EHRs) because it can pollute a patient's EHRs with diagnoses, prescriptions, treatments and other medical information not generated by them—and, too often, without their knowledge. Such corrupted records can come back to haunt innocent patients in the future.

The annual HIMSS report is based on a survey of 150 information security leaders at U.S. hospitals and hospital systems and various non-acute care environments like doctors' offices, behavioral health and long-term care facilities and home health service providers.

# MOUNT SINAI TO TACKLE FOOD INSECURITY WITH FRUIT/VEGGIE "PRESCRIPTIONS"

Can subsidized medical "prescriptions" for fresh fruits and vegetables help low-income patients improve their health?

That's one of the questions two doctor-researchers at the Icahn School of Medicine at Mount Sinai hope to answer as they follow a group of 50 obese children and 50 adults with poorly controlled diabetes. All participants in Mount Sinai's new Powerfood program, who will have been identified as "food insecure," get affordable access to fresh fruits and vegetables.

The new pilot, which will begin recruiting participants in September, is led by Mount Sinai physicians Dr. Leora Mogilner, a pediatrician, and Dr. Victoria Mayer, an internist.

Powerfood was developed in partnership with three nonprofit organizations: Bridgeport, CT based Wholesome Wave, which has championed the prescription model with health providers around the country; the NY Common Pantry, a food pantry in the city that will screen families for food insecurity, and the Corbin Hill Food Project, a nonprofit food hub that distributes food from local farmers in the Bronx and Harlem.

Each family will pick up a \$20 box of fresh produce every two weeks, with the program footing half the bill. The rest can be paid for with SNAP or other public benefits.

# MT. SINAI, STONY BROOK TO AFFILIATE

The Manhattan-based Mount Sinai Health System and Long Island-based Stony

# Happenings Around Hamaspik

# GO SOUTH 9TH!

With every activity and item on its three-day itinerary branded with a "Go" theme, the residents of the South 9th Shvesterheim IRA, Hamaspik of Kings County's first group home meticulously managed since inception by the tireless Mrs. Malkie Cziment, enjoyed a vacation at the upstate Raleigh Hotel sprinkled and spiced with driving verbiage.

Each young woman wore a colored "Hamaspik On the Go" name necklace at departure from Brooklyn, enjoyed their midday meal from a "3-2-1 Go! Lunch

Box," played "Games on the Go" to fill their first vacation evening, and even collected a "Go Package" of frosty mints.

Of course, in the course of visiting about four venues upstate, they also managed to go boating, hiking, swimming, vegetable picking, hay riding, bowling, roller skating and—not to forget when your driving theme is "Go"—go-karting.

For South 9th, plans for person-centered family fun this summer were definitely—and, perhaps literally—a go.

# FORSHAY FOUND FABULOUSLY FAVORABLE IN FLEISCHMANNS

The Regis Hotel of upstate Fleischmanns, New York not only threw open its doors this past August to "the boys" of Hamaspik of Rockland County's Forshay Briderheim Individualized Residential Alternative (IRA), but its hearts, too.

The gentlemen opted for the popular resort town for their summer vacation this year, departing Monsey midday on Monday, August 22 and arriving at the hotel later that afternoon.

That was after their van and bus had first stopped at Bear Mountain State Park for an outdoor picnic lunch surrounded by breathtaking views, of course.

Naturally, the gentlemen and their support staff of four also had to take a travel break in Chester, New York, where the rigors of the road were rip-roaringly replaced by go-kart-track rounds at The Castle, a family fun center frequented during the seasonable months by Hamaspik. The young men also enjoyed The Castle's interior, replete with exhilarating games as it is.

Once at "Oppenheimer's," as the Regis is informally known for the family that owns it, no sooner had Hamaspik's vehicles been parked in the hotel's lot than hotel staff invite the new guests to park themselves in their lobby.

With their luggage unpacked and the gentlemen settled into their quarters, that acceptance was shortly expressed as staff graciously invited them into the main dining room for a sumptuous dinner.

Until their departure on Wednesday and all through their stay (which included local trips to a petting zoo, swimming, and a two-hour Hudson River boat trip), the Hamaspik party was made to feel right at home at the Regis.

"The people at the hotel were very respectful and friendly," reports Forshay IRA Manager Mrs. Sarah Fischer—a respectful friendliness that also included guests and employees alike showering Hamaspik staff with blessings for the work they do. "They were very nice to us—very accepting!"









Brook Medicine announced their collaboration on research, academic and medical programs, Crain's recently reported. The two organizations will team up on graduate and medical education and devise summer programs for undergraduate, graduate and postgraduate students. The agreement gives Mount Sinai a foothold on Long Island, where the city's medical centers have been seeking partners.

# NIGHT SURGERIES DOUBLE RISK OF PATIENT DEATH: STUDY

Hospital patients are likelier to die if they undergo a surgical procedure at night, according to research recently presented at the World Congress of Anesthesiologists.

Researchers with Montreal's McGill University Health Center analyzed all surgical procedures over a five-year period at Montreal's Jewish General Hospital—some 41,716 elective and emergency procedures in all

After adjusting for age and overall American Society of Anesthesiologists risk scores, they found that patients were 2.17 times more likely to die during nighttime surgeries than during daytime procedures, with those undergoing procedures later in the day 1.43 times more likely to die than

those undergoing it during regular daytime

There are numerous potential reasons for the increased risk, according to the researchers. For example, provider fatigue as the day wears on is a major concern, which has led certain providers to allow nurses to nap during breaks. It's also possible treatment is delayed in some cases due to lack of room availability or patients being too sick to be postponed prior to treatment.

Despite these risks, research indicates providers are increasingly hiring doctors to work overnight shifts.

# CLEVELAND CLINIC REPLACING ALL LIGHTING WITH CHEAPER, "GREENER" BULBS

How's that for a bright idea?

Hospitals sure suck up a lot of electricity, what with all the electric and electronic biomedical equipment in regular usage—never mind all the computers. And that's not even counting the thousands of light bulbs illuminating hundreds of thousands of square feet across hundreds of rooms, hallways, lobbies and public areas.

That's why the Cleveland Clinic, a vast medical complex that is one of the country's top hospitals in a number of specialties, is now replacing all its fluorescent light bulbs with more energy-efficient, cheaper and environmentally friendly "green" light bulbs.

The project is said to be the largest hospital lightbulb-change operation ever.

The vast campus-wide retrofit, which will take months and which has created 20 new jobs, will replace 250,000 fluorescent lights in all of the system's facilities with LED lights—which last up to ten years and are mercury-free.

Lighting accounts for 16 percent of Cleveland Clinic's total energy use; the retrofit is projected to save the health system about \$2 million annually in electricity consumption.

# MEDICAL GROUPS SPAR OVER OPERATING-ROOM DRESS CODE

A statement issued earlier this summer by the American College of Surgeons (ACS) outlines what it considers proper hospital operating room (OR) attire—based on "professionalism, common sense, decorum and the available evidence."

However, "In response to numerous calls from members and nonmembers," the Association of periOperative Registered Nurses (AORN) released its own statement on August 16 about the ACS statement:

"Of particular concern to AORN, and its membership, is the introductory statement, 'The ACS guidelines for appropriate attire are based on professionalism, common sense, decorum, and the available evidence.' Regulatory agencies, accrediting bodies, and patients expect health care organizations to follow guidelines that are evidence based rather than conclusions based on professionalism, common sense, or decorum."

Does AORN have difficulty with professionalism, common sense or decorum?

# HOSPITALS SLOWLY GETTING OUIETER

With endless monitors beeping, clogs squeaking on tile floors, automatic doors and rolling cots whirring, caregivers rattling off jargon and patients moaning, nothing sounds like a hospital—making it a hard place to sleep, and heal, in.

But a small group of diverse experts have been reducing hospital noise in recent years. Among their changes are wearable silent alarms alerting nurses to changes in patient vitals, designing wards to provide private patient rooms, and even changing guidelines to allow nurses to close patient doors behind them.

# **SCIP-ING TRAINING AT HAMASPIK ROCKLAND**

Keeping its front-line support staff on the cutting edge of competence as it does, Hamaspik recently certified (or recertified) a group of Direct Support Professionals (DSPs) in Strategies for Crisis Intervention and Prevention (SCIP), the OPWDD's official rules for how to safely protect people with disabilities from physically harming themselves or others, including staff.

At an August 18 training session on its central premises, Hamaspik of Rockland County had close to a dozen agency MSCs both new and old receive training (or a refresher) in SCIP.

A professional trainer spent several quality hours guiding the staff through a number of crisis scenarios, with all emerging equipped to defuse any situation—and to prevent them in the first place.





# THE SUN(SHINE) LIVES AT DINEV

Despite several days of torrential downpours and sheets of gloomy gray cloud punctuating this summer's otherwise glorious stretches of blight blue-sky times, the residents of Hamaspik of Orange County's Dinev Inzerheim Intermediate Care Facility (ICF) have remained sunny all season long thus far—thanks in small part to

the "summer sunnies" they lovingly made by hand one summer day. The sun shapes, comprised of pretzel sunbeams radiating from orange-sprinkled cookies, were so bright, cheery and positively yummy that you could just eat them up—which residents did. (But not before a caring staffer sent in this photo!)

# **MOTOR CARS FOR FOREVER-FRIEND STARS**

Well, a van, at least.

The popular and growing STARS program powered by Hamaspik, geared for the community's highest-functioning young women, got a new van this August. The brand-new passenger vehicle helps the program beneficiaries regularly get out and about around town, shuttling to and from their plethora of daily off-site life-skills activities.

Speaking of activities, the STARS program—under the leadership of director Mrs. Esty Schonfeld and capable staff—keeps plenty busy on its own premises! Among its stimulating and therapeutic activities were the painting of ceramic forms—turning the blank white shapes into stunning kaleidoscopes crackling with color, life... and more than a little friend-ship.









E16 HAMASPIK GAZETTE SEP. 2016 • ISSUE NO. 142



# Dementia sniff test still far from mainstream usage

Another two studies at Toronto's Alzheimer's convention had researchers following their noses—well, at least those of study participants, and rather literally.

The studies found significant overlap between senior participants' onset and progression of Alzheimer's and other forms of dementia—and increasing loss of ability to detect odors.

While some of the evidence of the stud-

ies indicate a fairly direct correlation between degeneration of the brain and loss of ability to smell, researchers both involved and uninvolved with the study say that a sniff test to diagnose Alzheimer's is far from mainstream usage.

What's more, it may never be used as a single definitive test to diagnose dementia but rather, as an additional tool for doctor to confirm a suspected diagnosis.

# For long life, family trumps friends

Huge families featuring multiple generations of siblings and cousins centered on patriarchs and matriarchs are anything but quaint throwbacks, research now shows.

A review of several national health databases on seniors found that older adults who reported not being close to their family

# PATIENT, 86, LEFT IN DIALYSIS CLINIC

Some way to spend your weekend!
On the afternoon of Saturday, August 13, firefighters had to break into the Fresenius Medical Care center in Methuen, Massachusetts after a dialysis patient, an 86-year-old woman, was left in her treatment chair alone after center staff left and locked up for the day. The woman, who was not hurt, was transported home via ambulance.

had a 14-percent risk of passing away in the next five years—while those reporting being close with family other than spouses had about a six-percent risk.

According to lead researcher James Iveniuk of the University of Toronto School of Public Health, not only do family relationships trump friendships, but people not close to their family also have greater risk of suffering heart attacks or strokes.

"There are strong expectations about your family taking care of you, particularly when things are burdensome or frightful for you, like when you are in ill health," Iveniuk explained to *HealthDay News*. "Your family is supposed to be there for you."

Which, of course, is the way it's supposed to be—and the larger the family, the more loving people you'll have to be there for you.

# **BRAIN-STRAINING**

# JOB MAY HELP WITH BRAIN DAMAGE

Among the more fascinating preliminary studies presented at the most recent Alzheimer's Association International Conference in Toronto, Ontario was research indicating that a job that makes you think and cogitate more may offset the effects of blood-vessel brain damage more.

It may even protect against Alzheimer's, the researchers cautiously added.

In an analysis of data from patients with normal cognition in the Wisconsin Registry for Alzheimer's Prevention (WRAP), patients with more white matter hyperintensities on brain scans also tended to be those with mentally challenging occupations.

Those who worked predominantly with other people—rather than with data or with physical things—garnered the most

protective effects, researchers said.

Researchers said that people with higher occupational complexity appear to be better able to withstand the pathology associated with Alzheimer's disease and perform at a similar cognitive level as their unaffected peers.

The data suggest that social interaction plays a unique role in cognitive reserve.

The idea of cognitive reserve has gained widespread acceptance in the Alzheimer's field. It refers to the retention of cognitive function despite having pathology in the brain normally associated with dementia.

Cognitive reserve is typically associated with greater educational attainment or complex work environments—raising the question of whether modifiable factors could protect against Alzheimer's.

# NEW ALZHEIMER'S DRUG FEELING THE BLUES

A new drug that's supposed to block the build-up of plaques and tangles in the brains of people with Alzheimer's has failed in a large trial.

The drug, a derivative of the common surgical dye methylene blue, was tested on close to 900 seniors in 16 countries who have mild to moderate Alzheimer's disease. About half received the drug and the other half got a placebo.

Over the 18-month study, participants getting the experimental drug LMTM fared no better in brain cognition or function than

those getting the placebo.

However, in secondary results, patients exclusively getting LMTM (and no other Alzheimer's medication) did show 30 percent less brain atrophy by study's end than those taking it together with current dementia medications like donepezil (Aricept) or memantine (Namenda).

The drug, produced by maker TauRx, was hoped to thwart the harmful buildup of tau, the tangled proteins believed to increasingly interfere in brain function and cause the progressive memory loss, dementia and brain damage of Alzheimer's.

The failed trial comes on the heels of a recent small study of methylene blue and short-term memory that had the opposite effect. Volunteers in that 26-person study who had imbibed the surgical dye one hour before a functional magnetic resonance imaging (fMRI) scan showed greater memory-forming brain function than those who did not.



HAMASPIKCARE EMERGENCY HOTLINE

877.928.9000