

Clinical Update

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Major Players: Nurse Practitioners

At University Hospital, 120 nurse practitioners make a profound contribution to the quality and scope of services. Page A2

Paving the Way to Adult Care

For teens with complex neurodevelopmental conditions, a pioneering institute targets the critical transition from pediatric to adult care.

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Unlocking More Genetic Mysteries

With a \$1.45 million NIH grant, SUNY Upstate biochemist David Amberg PhD continues his quest to analyze complex genetic interactions in cells. Page A6

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Nurse Practitioners: Major Players in Modern Medicine

s medicine advances, our medical professions evolve to meet ever-more-complex demands. Nurse practitioners exemplify this forward march in medicine – and play a pivotal role in healthcare today.

"Here at University Hospital, we are large in numbers and very diverse in our range of responsibility," reports Susan Shaw MS, PNP, a nurse practitioner in the hospital's Center for Children's Cancer and Blood Disorders. "We also bring tremendous depth to our clinical positions."

"Our patient surveys indicate very high patient satisfaction with the nurse practitioners – their skills and concern are so apparent," notes Mary Ann Merklein, director of Medical Staff Services. "Often, they are the patient's first point of contact at the hospital. Whether they are examining patients, putting them at ease before surgery or taking the time to explain a procedure or aftercare, the patient always comes first."

Advanced

To become a nurse practitioner (NP) in New York State, a registered nurse currently needs a master's degree, significant clinical experience and advanced practice skills in diagnosis and treatment. The NP role was first created in 1961, in anticipation of physician shortages. Nurse practitioners work in concert with physicians but are permitted, in this state, to independently prescribe medication and treatment.

University Hospital in Syracuse employs 120 nurse practitioners. To promote understanding and recognition of their complex roles, in 1999 these highly trained professionals formed the Medical Alliance with the hospital's physician assistants (who will be featured in the next issue of *Physicians Practice*). The Medical Alliance also sponsors monthly grand rounds geared to its members' interests.

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Diversified

Nurse practitioners can be found throughout University Hospital, assigned to such diverse areas as cardiac surgery, emergency psychiatry, oncology and pediatric HIV. Shaw – one of the first nurse practitioners to work at University Hospital – earned her PNP (pediatric nurse practitioner) – certification through SUNY Upstate's College of Nursing in 1979 and completed a master's degree in nursing at Syracuse University in 1993. Today, nurses may simultaneously earn a master's degree in nursing and nurse practitioner certification, through SUNY Upstate's College of Nursing.

Specialized

Nurse practitioners focus their training around a specific medical specialty. Shaw's specialty is pediatric oncology. As coordinator of the Kids Now Off Therapy (KNOT) clinic, she monitors childhood cancer survivors for medical and psychosocial late effects of their cancer treatment. She is also involved, at the national level, in research into these late effects – and in educating teachers and other medical professionals about managing these unintended but disruptive consequences.

Comprehensive

Pediatric oncologist Irene Cherrick MD appreciates the depth of the nurse practitioners' expertise. "As a physician caring for children who are extremely ill with cancer and blood disorders, nurse practitioners are an invaluable asset," she says. "Not only do they assure excellent physical care of these children, they provide complete care – including spiritual, emotional and psychosocial support for the patient and the entire family. The nurse practitioners' training fosters this total care."

Knowledge is Power

Many nurse practitioners embrace the opportunity to teach. Mary MacBlane MS, PNP, works in neurodevelopmental pediatrics at University Hospital, with patients who have spina bifida, autism and inherited metabolic disorders. In addition to coordinating care for these patients, MacBlane is often the point person for educating families. "Mary plays a central and critical role in the functioning of our clinical programs," notes Louis Pellegrino MD, a neurodevelopmental pediatrician at University Hospital. "She works tirelessly to assure that our patients receive the proper care, and is frequently the 'go-to' person when problems arise. In her work, she exemplifies the special role of the nurse practitioner: she bridges the domains of the clinician and the nurse and is literally the 'glue' that holds things together. It is hard to imagine how our program would function without her."

> Editor's note: Check July's Physicians Practice to meet some of University Hospital's physician assistants, who also play a key role in health care delivery.

Gaining Ground Lisa Cico MS, NP, coordinator of

University Hospital's new Multidisciplinary Breast Cancer Program, is execu-



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Council, and lobbies on behalf of NPs in Washington, DC, and Albany.





Teens Moving On: Institute Targets Critical Transition From Pediatric to Adult Care

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First, the good news about children with neurodevelopmental disorders such as spina bifida or cerebral palsy: "The vast majority of these kids with complex conditions now survive into adulthood," reports Nienke Dosa MD, MPH (left) of University Hospital's Center for Neurodevelopmental Pediatrics.

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ow, the challenge - for both patients and providers. "These patients must make the transition from pediatric to adult medical care," says Dosa. "Our health care system also needs to catch up with these new patients."

Dosa was recently funded by the New York State Developmental Disabilities Planning Council to establish the "New York State Institute for Health Transition Training for Youth with Developmental Disabilities." This three-year project will establish a statewide infrastructure to support primary care physicians on both the giving and receiving end of the transition.

"Our mission is to improve access to care and the quality of care that is provided to youth with developmental disabilities in New York State," Dosa explains. "We will distribute a curriculum and create web-based tools to make it easier to find transition-related services, share medical records and work with publicly funded support services such as Medicaid service coordination."

Vulnerable

"Young adulthood is a vulnerable time for my patients," Dosa notes. "Often their parents have been the keepers of their health information. There may be an element of learned helplessness.

"It is also essential to understand the interplay between health and social outcomes for this population, given our nation's employment-based health insurance system - and the fact that nearly 30 percent of our youth ages 18 to 24 are uninsured," she says.

"This means that many of my patients drop out of the health care system just when that transition from pediatric to adult care should occur. Studies have documented, and I have personally seen, avoidable medical complications, and unnecessary hardships among my patients, because of this situation."

Community Collaboration

The new institute is a joint venture with University Hospital's departments of Pediatrics and Family Medicine. Other collaborators include the Burton Blatt Institute and the

School Nurses.

School of Information Studies at Syracuse University; Exceptional Family Resources; "Many of my patients drop out of the health care system just when that transition from pediatric to adult care should occur."

"I am very excited to work with these terrific grass-roots organizations," says Dosa. She recently hired Jeffrey Tamburo LMSW as project administrator for the institute. "Jeffrey brings a very important skill set. He has worked

Self Advocates of New York State: and

the New York State Association of

for more than 10 years in the field of supported employment and helped to establish Disability Mentoring Day in this community. He truly understands the contri-

bution health care providers can make to ready youth for full participation in society. Our goal is adolescents who are not just healthy, but healthy and ready to work."

> Editor's note: For more information about the new institute, please go to www.HealthyTransitionsNY.org

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& University Hospital Syracuse New Yor

Searching for keys to human genetic disorders

University Hospital, Syracuse, N

SUNY Upstate's David Amberg PhD awarded \$1.45 million NIH grant

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avid Amberg, PhD, associate professor of biochemistry and molecular biology at SUNY Upstate Medical University, has been awarded a four-year, \$1.45 million grant from the National Institutes of Health (NIH) to analyze and identify complex genetic interactions in cells. Dr. Amberg will use the cytoskeletal system of yeast to model the genetic interactions of complex systems. Research into genetic interactions in cells is considered vital to further understanding of human genetic disorders.

The NIH grant comes on the heels of a breakthrough - in identifying binary gene interactions - that Dr. Amberg and his research team reported in the Jan. 15 issue of Genes and Development. Dr. Amberg and his colleagues have developed a large-scale reverse genetic screen to identify complex haploinsufficient genetic interactions.

Haploinsufficiency occurs when an individual inherits only one good copy of a gene as opposed to the normal two copies. A resulting decrease in gene product can lead to human disease. For example, haploinsufficiency of "tumor suppressor" genes has been implicated in the development of certain cancers.

This new study from the Amberg lab measures the effects of being haploinsufficient for two different genes and demonstrates how frequently such bigenic interactions compromise cell function.

To illustrate this new approach, the researchers examined nearly 5,000 haploinsufficient yeast strains to identify more than 200 genes that, in combination, cannot tolerate a reduction in gene copy number for the actin gene.

Research into genetic interactions in cells is considered vital to further understanding of human genetic disorders.

"We knew that actin was an important gene, but we were still surprised at the large number of haploinsufficient interactions we uncovered," Dr. Amberg said. "This test case suggests that similar interactions in complex organisms can have major influences on phenotypes such as the development and susceptibility to disease."

This paper is one of the first examples of a large-scale reverse genetic screen that specifically looks at haploinsufficiency. It is expected that this kind of systemic analysis will be particularly useful in uncovering complex genetic interactions in other organisms, including the study of complex, human genetic disorders.

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