

FALL 2014

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25 Years of Saving Children's Lives: The Clinic for Special Children

 PENNSYLVANIA OFFICE OF
RURAL HEALTH



AGRABILITY FOR PENNSYLVANIANS

Helping Disabled Farmers
Continue to Do What They Love

TYRONE HOSPITAL

Securing the Future of Health
Care in Central Pennsylvania

URBAN AND RURAL HEALTH

A Patient's Perspective on
Receiving High Quality Care Close
to Home

message *from the* director

If you are like me, you've been reading the announcements of hospital and health system mergers and changes. It's a bit hard to keep track and to anticipate what might be coming.

According to a report due to be released in August 2014 by the North Carolina Rural Health Research Center, "hospital sales and buyouts are changing the face of health care in communities across the country with mergers escalating to levels not seen in more than a decade." The report asserts that "small rural hospitals are common acquisition targets for several reasons, including value-based purchasing, market share and cost control, and the strategies promoted by the ACA."

Data from the Pennsylvania Health Care Cost Containment Council (PHC4) indicate that, in 2012,



18 hospitals or hospital campuses in the commonwealth merged, changed name or closed. In 2013, 25 hospitals or hospital campuses faced the same situation, and as of June 2014, eight have merged or closed. Not included in these data are one Critical Access Hospital (CAH) that closed and other mergers between health systems that are in process.

These mergers can benefit rural health care delivery systems and the communities they serve by bolstering the financial viability of the hospital, increasing available services in communities, and linking facilities to larger systems. However, the cost to the community needs to be considered. More than two decades of economic impact research from the Center for Rural Health Works at Oklahoma State University have demonstrated that, in addition to education and government sectors, the health care sector is one of the top three economic drivers in any community, especially those in rural areas. Every

dollar spent locally on health care multiplies by at least one and a half times as those dollars are reinvested in other goods and services, adding, in some cases, \$70 million dollars to the rural county. That's a lot of dough for counties with populations of 40,000 or less. A strong rural health care system also makes those areas more attractive to businesses and retirees, adds significantly to the connectedness in communities, and assures rural residents that quality health care is available locally.

There are plenty of examples of creative initiatives that strengthen rural health care delivery systems. Consider the newly established Tyrone Regional Health Network that serves Huntingdon and Blair counties (see the article on page 8 of this issue of *Pennsylvania Rural Health*). Under the visionary leadership of the network's CEO and board of directors, acute, outpatient, ancillary, and specialty services have been combined into an integrated network that retains its rural roots while offering advanced services that are convenient to residents. This and other examples exist in Pennsylvania and across the U.S.

Quality health care. Close to home. It doesn't get any better than that.

Thank you for the work that you do every day to bring health care to the communities you serve, and as always, please let us know how your State Office of Rural Health can help.

Best wishes for the remainder of the year.

A handwritten signature in blue ink that reads "Lisa Davis".

Lisa Davis
Director



Cover Story: 25 Years of Saving Children's Lives: The Clinic for Special Children



Tyrone Hospital: Securing the Future of Health Care in Pennsylvania



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Pennsylvania Rural Health

Lisa Davis, *Director*

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25 Years of Saving Children's Lives: The Clinic for Special Children

CELEBRATING *25* YEARS



Clinic for Special Children

Twenty-five years can seem like the blink of an eye, a long time or even a lifetime. In the case of the Clinic for Special Children in Strasburg, Pennsylvania, no matter one's perspective, 25 years has proven to be immeasurable—and wonderful.

Immeasurable because one can't put a figure on saving lives.

By Susan J. Burlingame

Wonderful because a pediatrician, his wife, their leap of faith—and the team they surrounded themselves with—have created diagnostic tools, information, treatments, and protocols from which the rest of the world can benefit.

It started in 1989 when Dr. D. Holmes Morton, a Harvard-trained physician with an interest in metabolic genetic disease, traveled to Lancaster County to study glutaric aciduria type 1 (GA1), an inherited disorder that had affected three of the children of Aaron and Malinda Allyger. The Allygers were “Plain people,” a term describing Mennonite and Amish populations—descendants of Swiss Anabaptists who fled religious persecution and settled in Pennsylvania and other parts of the country beginning in the mid-1700s.

The Allyger's first child died in early childhood because of GA1. Their second was severely disabled by the disease. She depended on her parents for her every need until she passed away at the age of 40. A third child, 14 years old when Morton first went to the Allyger's home, had somehow escaped the brain injury and disability of her siblings.

“She gave all of us hope that this difficult disease could be treated,” Morton remembered.

While working to understand the apparently rare disease, Morton discovered that many other children in the Plain community had the same genetic disorder but had been misdiagnosed as having “Amish cerebral palsy.” His proper diagnosis and subsequent treatments, which included dietary modifications, planted the seed in Morton to do something completely unexpected: establish a rural medical clinic to serve the Plain people of Lancaster County, Pennsylvania. Without funding. Without a facility. Without a biochemical laboratory. And without an assured future.

Morton's medical school and residency colleagues told him a move to Lancaster County would end his promising career in academic medicine, but Morton did it anyway—a decision he has never regretted.

Funding for what Morton and his wife, Caroline, called the Clinic for Special Children wouldn't come from traditional sources. Requests for start-up monies had been declined by Children's Hospital of Philadelphia, Johns Hopkins, and the National Institutes of Health. Instead, funding came from the most unlikely of sources. Frank Allen, a staff reporter at the time for the *Wall Street Journal* took an interest in Morton's work and wrote a piece titled “Country Doctor: How a Physi-

cian Solved Riddle of Rare Disease in Children of Amish.” The story documented Morton’s quest as well as the success he had in treating glutaric aciduria. Within 10 days of the article’s publication in September of 1989, more than \$450,000 in private contributions came in, as did a Hewlett-Packard GC mass spectrometer (a critically important and expensive piece of diagnostic equipment that can detect glutaric aciduria in urine samples), donated by David Packard himself. Additional funding (then and through the years) largely has been through auctions run by members of the Plain community. To this day, the clinic receives no formal public funding and continues to thrive through the generosity of the people it serves.

The clinic’s facility came in the form of a timber frame building, “raised” between two Amish farms in 1990 by Amish, Mennonite, and other community volunteers. A simple structure externally, the building houses sophisticated exam rooms, a biochemical and molecular genetics laboratory, and meeting rooms for training and gathering.

Winning over the people of the Plain communities was another challenge to overcome, but people whose children were saved quickly grew comfortable, accepting the sophisticated science and medicine used by Morton and his colleagues—and ultimately spreading word about the clinic’s approach and success to other communities.

Said one Old Order Mennonite who lost a child to severe combined immunodeficiency but who now has a healthy young daughter due to the clinic’s swift intervention: “We don’t embrace technology, but if it’s used for saving a life, we are not against it. This is a place that treats people like family, like every child is their own child.”

The clinic was established to serve the largely uninsured community where GA1 and maple syrup urine disease—another devastating inherited genetic disorder—affect one in 400 children. Morton and his colleagues believe that children with genetic disorders need quick diagnosis and immediate, appropriate care. The Clinic for Special Children, for which Holmes and Caroline Morton risked virtually everything, was a risk worth taking.

Since that day in 1989, the Clinic for Special Children has grown to include experts devoted not only to providing primary medical care for children from Plain communities but also to integrating science and clinical medicine. Medical director Dr. Kevin Strauss, laboratory director Erik Puffenberger, PhD, and Morton have been producing high-level, research-driven outcomes, resulting in more than 80 peer-reviewed papers to date.

“It is important to remember that advances in molecular science only reveal what can be done with genetic information,” commented Strauss. “Perhaps the Plain people can teach us something important about what should be done with it. The Old Order communities measure the value of medical research not in grant awards, publications or academic promotions, but in human terms: alleviation of pain, prevention of disability, equitable delivery, and fair cost. They understand that to translate genetic information into better public health, one must first commit to caring for individuals.”

Strauss holds a medical degree from Harvard University. He oversees all clinical services and associated research, and he conducts medical outreach clinics in other areas of the state. Puffenberger holds a doctorate in genetics from Case Western Reserve University. He oversees all laboratory activities and is responsible for clinical and basic research. The clinic’s newest physician, pediatrician Dr. Katie Williams, PhD, holds a medical degree and doctorate in nutrition from the University of Wisconsin-Madison. Williams helps manage daily clinical care and the clinic’s on-call service.

In addition to patient care, research, and outreach, the clinic’s staff offer midwife and community education, screening programs, and other services. To honor the legacy of the late Dr. Mary Ellen Avery, a pioneering pediatrician and scientist who once served as mentor to Morton, the clinic established the Avery fellowship in 2012. The fellowship provides a one-year educational and research experience for a bright student with interest and training in pediatrics, genetics, bioinformatics, newborn screening or public health in hopes that he or she will consider a career as a physician-scientist in an underserved community.

In 1989, the Clinic for Special Children had a caseload of only 100 patients. Twenty-five years later, there are more than 1,000 active patients (2,600 total) from all over the United States and the world.

Starting with treating two genetic disorders (glutaric aciduria and maple syrup urine disease), the clinic’s physicians now treat patients with 150 unique mutations—and they discover an additional four to five every year. Where it once focused solely on metabolic disorders, the clinic’s clinical staff and scientists now diagnose and treat conditions related to the heart, liver, brain development, seizure/neuro disorders, immune disorders, endocrinology, hearing loss, and more.

With an on-site certified metabolic and genomics laboratory providing assays including amino acid quantitation, urine

organic acid analysis, real-time molecular diagnostic testing, molecular cytogenetic analysis, exploratory gene mapping, and more, the clinic's physicians can diagnose children's conditions quickly—and immediately begin the medical and dietary interventions that can save their lives.

“From the beginning, the clinic's laboratory has functioned as a core facility to aid in the diagnosis and management of genetic diseases,” explained Puffenberger. “Our lab contains sophisticated equipment usually found in academic research labs. We have designed many novel tests for detection of various metabolites and mutations. By bringing these assays into the clinic, we are able to provide rapid, high-quality testing at a fraction of the cost that these families would pay elsewhere. Families willingly participate in research and use our laboratory service because of the responsibility and trust we share in the care of vulnerable children.”

Before the clinic was founded, families whose children were affected by complex inherited diseases would see their personal assets, as well as community resources, absorbed by extensive testing and costly hospital stays. By making office visits, diagnoses, laboratory tests, and treatment protocols affordable, and by preventing disabilities and reducing disease-related hospitalizations, the clinic improves out-

“Special children are not just interesting medical problems, subjects of grants and research. Nor should they be called burdens to their families and communities. They are children who need our help, and if we allow them to, they will teach us compassion. They are children who need our help, and if we allow them to, they will teach us love. If we come to know these children as we should, they will make us better scientists, better physicians, and thoughtful people.”

—Dr. D. Holmes Morton

comes for patients, and reduces the cost of care. The economic savings to patient families and the Plain community is an estimated \$40 million annually.

“This clinic is trying to take medicine out of the big centers and put it in the community—not only medicine but genomics and genetic information—and to use that to form health care services in a way that really makes that information more valuable,” said Morton. “It really doesn't matter whether you're working with Amish or Mennonite people or other people in rural communities. The truth is you can do this kind of work anywhere; you will find clusters of genetic problems that affect people's health everywhere.”

A common misunderstanding is that the diseases they see at the clinic are simply “odd diseases that only affect Plain people,” he said. “These genetic disorders came from Europe 400 years ago, and the diseases they cause are found everywhere—here, in Europe, and in other places.”

Morton and his colleagues have seen their work expand far beyond Lancaster County; they are frequently invited to speak at conferences and symposia across the country—sparkling interest and partnerships from medical centers that once disregarded Morton and his work.

“Children's Hospital in Philadelphia, Children's Hospital of Pittsburgh, and DuPont Hospital have all become very interested in working with us,” added Morton, citing a new study of the hemolytic disease pyruvate kinase in partnership with Boston Children's Hospital, Stanford University, and an academic medical center in Italy. “They see the work as something interesting and unique, and they like to have their residents learn about it. “That's different from when we first established the clinic when there was a lot of struggle to get recognized as a valid medical service,” Morton continued.

From a staff of three in 1989 (Dr. and Mrs. Morton as well as office manager Rebecca Smoker, who retired in December 2013), the clinic now has a staff of 14.

“I believe the success of this place is driven by the need within the community for the kind of health care we provide,” said Morton. “There's no question about the fact that people came together to raise money and build this clinic because they need it. And from a physician's point of view, this is interesting work. People who are training should really look at this as a job option that's interesting and different and needed. There ought to be a lot of clinics like this one.” And indeed there will be.



Amish children play in the hallway of the Clinic for Special Children (above). At left, the clinic in Strasburg, Pennsylvania sits in an idyllic setting. The clinic was built by Amish, Mennonite, and other volunteers.

The Central Pennsylvania Clinic – A Medical Home for Special Children and Adults, modeled after the Clinic for Special Children and spearheaded by Dr. Morton and his brother, businessman Paul Morton, will soon open in Belleville, Pennsylvania.

Substantial start-up monies have been raised through auctions, private contributions, hymn sings, free-will church collections, and a benefit dinner. In partnership with Children’s Hospital of Pittsburgh, which has pledged to match donated funds up to \$400,000, the new clinic will serve populations of people in central and western Pennsylvania for whom the Strasburg facility has been an inconvenient distance away.

It is Morton’s fondest hope that the Clinic for Special Children will serve as a model for similar rural community efforts in other states. “We happily share our ideas and information with others,” he said.

“There’s this tremendous bias that it’s only these strange Amish and Mennonite people who have genetic diseases and that genetic disease among the rest of the population is rare. Neither of those assertions is true,” he added. “Once you know the cause and the solution, and you can translate the science into cures, you can share the information for other doctors to use in Brazil or Saudi Arabia or India ... or anywhere.”

For 25 years—the blink of an eye, a long time, a lifetime ... or all of the above—the Clinic for Special Children has prevailed: an immeasurable, wonderful contribution to medicine and science.

For more information about the Clinic for Special Children, visit clinicforspecialchildren.org or call 717-687-9407.

AgrAbility for Pennsylvanians:

Helping Disabled Farmers Continue to Do What They Love

By Susan J. Burlingame

“If it wasn’t for AgrAbility, I wouldn’t be able to stay in this. And I would hate to give it up.”

Rose Sproat, from Dawson, Pennsylvania, loves dairy farming—an activity she began when she got married 42 years ago. Her cows have been a source of both enjoyment and income for decades, but milking cows the conventional way (surge milking) took its toll on Rose’s knees. For six years, she considered giving up dairy farming, even switching to raising beef cattle for a time, but she “just couldn’t give up the dairy.”

Recently, Sproat learned she didn’t need to give it up. AgrAbility for Pennsylvanians provided a solution.

The National AgrAbility Project is a program sponsored by the U.S. Department of Agriculture that supports projects in 24 states. These state-based programs provide assistance to farmers, ranchers,

other agricultural workers, and farm family members impacted by disability or long-term health conditions. People who have disabilities ranging from arthritis to hearing loss, and from back injury to brain injury, rarely want to—or can afford to—give up their livelihoods when they face hardships related to existing or acquired disabilities.

A farmer can contact AgrAbility directly, or a referral can be made by friends, Penn State Extension educators, or others. AgrAbility project managers make visits, assess situations, and recommend solutions ranging from physical and occupational therapy to equipment modifications. During an assessment, project managers meet with farmers and tour both the farm and the house.

AgrAbility for Pennsylvanians is coordinated by Penn State—Pennsylvania’s land grant institution—in partnership with the Pennsylvania Office of Vocational

Rehabilitation (OVR) and the Pennsylvania Assistive Technology Foundation (PATF). Connie Baggett, PhD, associate professor of agricultural and extension education, has been the director of the AgrAbility for Pennsylvanians project since its inception in 1994.

“Farmers don’t have disability insurance like the rest of us, but they need help when they’re experiencing difficulty with the work they do,” Baggett said. “OVR and PATF have a good understanding of what farmers go through, and they help farmers purchase or finance the modifications, therapies, and equipment we recommend.”

Clients fall into two categories, Baggett explained, those for whom OVR provides funding (12-15 customers per year) and AgrAbility clients who are not eligible for OVR funding and must find other ways to purchase the recommended farm equipment modifications (20-30 per year). PATF helps farmers in the second category find low- or no-interest loans to purchase the equipment they need to meet their needs.

Susan Tachau, executive director of PATF, said in addition to helping farmers who do not receive funding through OVR, the organization develops outreach materials to let farmers know about AgrAbility. “We are trying to make a connection to a community that is very independent. We know the information and assistance that AgrAbility can



provide will make a difference for farmers and their families. There are work modifications and equipment and housing adaptations that will make it possible for farmers to continue with production agriculture.”

Originally funded by the federal Assistive Technology Act, PATF “understands the disability world,” Tachau continued. “We make sure our materials are clear, and we provide up-to-date information, helpful tips, and referrals to other resources. It’s important to make sure we are communicating with each other and working together in partnership—AgrAbility, PATF, and the farmers.”

“A small number of farmers feed the entire world,” added Erica Bobbitt, PhD, project coordinator and AgrAbility for Pennsylvanians case manager. “They do important work that we all benefit from, and they love their work. It’s so gratifying to be able to help people continue to do what they love. AgrAbility makes people’s lives better.”

Solutions can be as simple as adding attachable steps to a tractor to make it easier to climb into or, in Rose Sproat’s case, installing a new recessed milking parlor, which she has been using since March 2014. She now milks her cows at eye-level. No more knee-bending. “I love milking again, and I never mind going out to the barn,” she said. “AgrAbility made all the difference in the world.”

For more information about AgrAbility for Pennsylvanians, visit extension.psu.edu/business/agrability or contact Connie Baggett, PhD, associate professor of agricultural and extension education at Penn State at 814-863-7415.



Rose Sproat prepares to attach the milking machine to a Holstein cow in her new milking parlor at her dairy farm in Dawson, PA (Fayette County). AgrAbility for Pennsylvanians worked closely with OVR to get help for Rose.

Tyrone Hospital: Securing the Future of Health Care in Central Pennsylvania

With increasing frequency, small community hospitals in Pennsylvania are being acquired by large hospital systems—a trend many believed would impact Tyrone Hospital in Blair County.

During a June 3, 2014, press conference, however, health care leaders, government officials, and community members who gathered for a major announcement heard just the opposite. Instead of being acquired by a system, Tyrone Hospital would remain an independent community hospital with a new name: Tyrone Regional Health Network (TRHN).

Chosen to better describe the community-based health care network that has evolved over the past few years, the name reflects the collaborative relationships forged between the hospital and other health care providers and organizations. A new logo for TRHN depicts a circle in motion, representing growth and evolution as TRHN continues to meet the health needs of area residents.

“We are much more than a hospital,” said TRHN CEO Stephen C. Gildea, FACHE. “We have become a network of organizations that are working in a collaborative manner to not only provide high-quality health care, but also services and programs that are aimed at keeping people healthy and preventing illness and disease.”

Since 1954, Tyrone Hospital has been an economic catalyst for the region—with an estimated \$33 million impact in FY 2013, according to a report released by the Hospital and Healthsystem Association of Pennsylvania. The hospital has focused on building collaborative relationships with large health care systems and other small, local providers to gain the economies of scale needed to maintain operational efficiencies and provide well-integrated health care services across the continuum of care. Tyrone Hospital is one of the state’s 12 Critical Access Hospitals (CAHs).

The hospital has responded to health care industry shifts by creating a more wellness-based model, focused on disease prevention, early detection, and early intervention. It provides health education programs to local employers and community organizations, hosts regular community health and wellness events, and recently opened a fitness and wellness center.

Crediting Tyrone Hospital’s philosophy of collaboration for both its strategic development and its ability to maintain its status as an independent, locally governed, community hospital, Gregory Kimble, D.O., chief medical officer, said: “We have a new logo, a new identity, and a blueprint of our new home. However, our mission remains the same: providing high quality health care to the residents of Tyrone and the surrounding communities.”

In addition to changing its name and reaffirming its purpose, TRHN will undertake an extensive renovation of Tyrone Hospital, including a 38,000 square foot expansion. The Tyrone Hospital Foundation is preparing to launch a \$20,000,000 capital campaign to support the renovation and is aiming to generate 10 percent of the campaign goal through community support. The hospital also kicked off its 60th anniversary of serving Tyrone and surrounding communities.

“Greatness and quality are not found in names, buildings, or programming. They are found in people,” concluded Kimble. “The people who make up TRHN...are the reason we are here today. They remain our greatest asset and reason for our bright future.”

For more information on the Tyrone Regional Health Network, contact Lannette Johnston, MS, BSN, RN, director of outreach programs, at 814-684-1255, ext. 1800 or to ljohnston@tyronehospital.org.



A Medical Student's Perspective

By Ashley Baronner

This column chronicles Ashley Baronner's experiences as a medical student in the Physician Shortage Area Program at the Sidney Kimmel Medical College in Philadelphia, formerly Jefferson Medical College. Ashley is the daughter of Larry Baronner, PORH's rural health systems manager and deputy director.



With one year of medical school now finished, I have spent a lot of time reflecting on this whirlwind of a year. During the first day of our orientation, one of our academic advisors drew a picture depicting the emotional rollercoaster that every medical student rides over the course of the year. The nadirs represented the most stressful weeks of challenging courses during the coldest, darkest weeks of winter,

as well as the sunny days of May when we were confined to cubicles studying the brainstem for our neuroscience course. The highlights of the academic year included our physiology course, which was the most clinically relevant, and the feelings of accomplishment associated with finishing each curriculum block. Despite the accuracy of the rollercoaster depiction, I prefer the simple summary provided by my first anatomy professor. Every morning before lecture, he would frame our experience by stating that we were “living the dream.”

During one year, I learned more that I ever imagined was possible about anatomy, biochemistry, physiology, and neuroscience. I also greatly improved the efficiency of my studying and discovered the benefits of studying with my classmates. Each block consisted of a 1,000 page syllabus, a wide range of lecturers, labs, problem-solving sessions, and grand rounds with patients to increase the relevance of our detailed course material. Even though I was not immune to the feelings of overwhelming stress and fatigue during the most difficult periods of my first year, I am incredibly grateful to be in medical school getting the knowledge, skills, and insight necessary to become an adept physician. It is a privilege to learn from highly respected PhDs, clinicians, and patients.

In order to maintain this optimistic “living the dream” perspective, I was engaged in numerous curricular and extracurricular experiences during the year, which have continued into the summer. Jefferson's Introduction to Clinical Medicine course provided opportunities to shadow clinicians, interview patients, practice physical diagnosis skills, and discuss the humanistic side of medicine. I felt that this course helped me to develop a solid foundation to interview patients in a sensitive and empathetic manner. However, my experiences at

JeffHOPE (Health Opportunities, Prevention, and Education) have been the most enriching. JeffHOPE is a free, student-run clinic, which provides care to the medically underserved men, women, and children of Philadelphia. The clinic also educates patients on health maintenance and the prevention of chronic illnesses, while allowing students to learn from each other to become stronger clinicians.

On numerous occasions, I have experienced the rewards of applying my knowledge gained from the classroom to patients who otherwise would not have been able to receive medical advice and treatment. The patients at JeffHOPE are often homeless, victims of domestic violence or experiencing other immense hardships that I cannot fully comprehend. However, my experiences have helped me to set aside my personal biases and form a partnership with each patient to improve his/her health and quality of life. I have developed the communication skills required to discuss difficult topics such as smoking cessation, explain the benefits of the pneumococcal vaccine, and convey the importance of many other topics pertaining to health and wellness behaviors. The process of taking a medical history, listening carefully to a patient's story, performing a physical exam, and presenting my findings to the physician leading the clinic has helped me to see the bigger picture of my medical journey.

This summer, I am continuing to volunteer at JeffHOPE in addition to my job as a research assistant in the Department of Family and Community Medicine at Jefferson. As a member of the Physician Shortage Area Program, I was offered this position to gain more experience pertaining to family medicine. I am working on a project at the Jefferson Center for Interprofessional Education (JCIPE) evaluating a longitudinal curriculum designed to improve chronic illness care by promoting patient-centered and team-based education. I am enjoying being involved in research pertaining to the Patient Centered Medical Home model, since I intend to pursue a career in primary care. Furthermore, my shadowing opportunities have expanded my horizons to include the world of primary care for an urban population. The dynamic patients, wide variety of medical ailments, and intricacies of chronic illness in this population have made it easy to continue learning new information every day. While the summer following the first year is certainly one of the highest points in medical school, I feel incredibly fortunate to be “living the dream” at Jefferson.

Health Information Technology Use in Critical Access Hospitals: Results of a Study in Two States



By Madhu Reddy, PhD and Bryan Steitz
College of Information Sciences and Technology, Penn State

Health information technology (HIT) is defined by the U.S. Department of Health and Human Services as “the application of information processing involving both computer hardware and software that deals with the storage, retrieval, sharing, and use of health care information, data, and knowledge for communication and decision making.”

In short, HIT changes the way hospitals interact with patients, the way doctors interact with each other, and the way information is shared.

HIT tools can include electronic health records, “ePrescribing,” secure messaging, and other options that ultimately serve to both improve health care delivery and reduce operating costs at hospitals both large and small.

Critical Access Hospitals (CAHs) can benefit from improved access to HIT tools, but implementing HIT can be complicated and expensive. While many large hospitals have both the resources and personnel, small rural hospitals often do not.

To find ways to assist CAHs in accessing and implementing HIT, as well as to identify the associated challenges and benefits of the technology, researchers in Penn State’s Department of Information Sciences and Technology conducted a series of national surveys examining HIT access issues with CAH leadership in 2012 and 2013 with input and assistance from the state offices of rural health in Pennsylvania and New York.

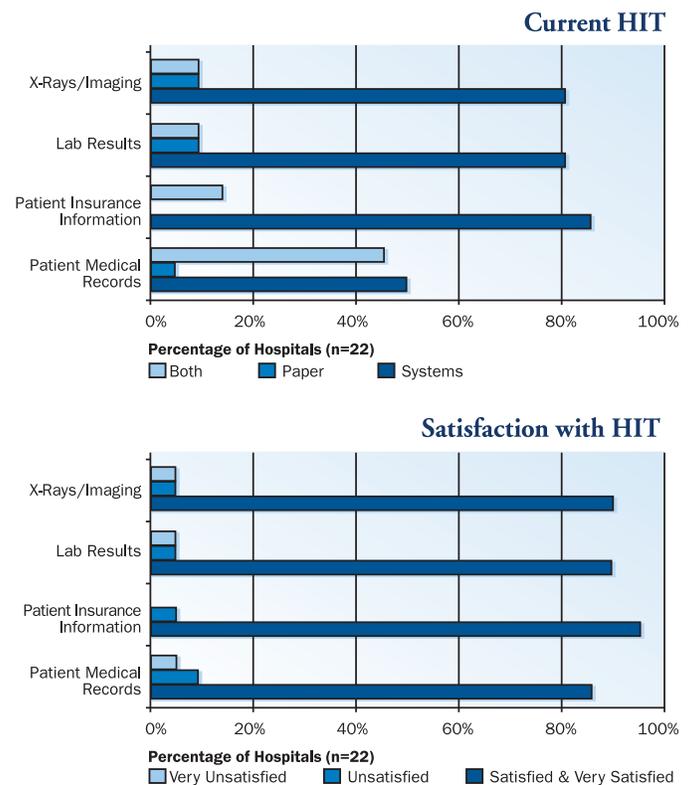
Researchers also conducted an on-line assessment of 24 CAHs in New York and Pennsylvania about HIT use. The assessment asked participants to identify current HIT resources and to report frequency of use and satisfaction with systems in place. Twenty-one participants provided usable responses, offering the researchers new insights into HIT use in CAHs.

In analyzing the responses, the researchers said they were surprised to find information contradicting earlier assumptions. “We did not expect to see as much widespread use of HIT as we saw in the responses,” noted Madhu Reddy, associate professor of information sciences and technology at Penn State and lead researcher on the project. While the “conventional view” indicated that CAHs use HIT either minimally or not at all, the assessment found broad use among CAHs in areas such as x-ray/imaging, lab results, patient records, and patient health information (figure 1). The researchers also found that most users of HIT at CAHs were either satisfied or very satisfied with the systems in place (figure 2), again contradicting assumptions that there was widespread dissatisfaction with HIT programs.

Though the research sample was small, and the Penn State researchers urge caution in interpreting the research results, they are confident the participants represented the broader CAH population fairly accurately. They concluded that further investigation will need to be conducted to answer two important questions:

- 1) What specific types of HIT are most useful for CAHs?
- 2) What are the key factors for successfully implementing HIT in CAHs?

The ultimate goal, researchers reported, is to better support HIT implementation at CAHs, leading to better patient care by saving time and cutting costs. “CAHs face a number of challenges in the changing health care environment. However, effectively implementing the appropriate types of HIT can help address some of these issues,” commented Reddy.



This research was supported, in part, by grants from The Commonwealth Fund, the National Network of Libraries of Medicine Middle Atlantic Region and The Tronzo Endowment for Medical Informatics. For more information, contact Madhu Reddy, PhD, associate professor of information sciences and technology at Penn State at 814-863-6316 or to mreddy@psu.edu.

Pennsylvania Department of Health's Programs to Support the Increase of the Primary Care Workforce

By Robert Richardson, Director, Bureau of Health Planning, Pennsylvania Department of Health

Recruiting health care providers for service in rural and underserved communities has always been a challenge in Pennsylvania and nationally. This challenge escalates as the supply of primary care physicians and other primary care providers does not meet demand. This is true in many areas of the commonwealth and nation, but it is especially challenging in rural communities and communities facing economic and social disparities.

The Pennsylvania Department of Health's Bureau of Health Planning, Division of Health Professions Development (DPHD) is engaged in several initiatives designed to increase the number of primary care providers in underserved communities. Efforts of DHPD are targeted to the over 200 areas of the commonwealth that the U.S. Health Resources and Services Administration (HRSA) has designated as Health Professional Shortage Areas (HPSAs). Communities within these areas have a critical shortage of primary care providers. Programs of DHPD include the Pennsylvania Primary Care Loan Repayment Program, the J-1 Visa Waiver Program and the Community-Based Health Care Grant Program.

PENNSYLVANIA PRIMARY CARE LOAN REPAYMENT PROGRAM:

This program provides educational loan repayment for primary care providers who agree to a multi-year term of employment at a community-based health center located in an underserved community which provides care to all patients regardless of income or insurance. Physicians, dentists, nurse practitioners, nurse midwives, and physician assistants are eligible for this program that is designed to make employment in underserved areas more attractive to the provider. Between 50 and 75 providers participate in this program annually.

J-1 VISA WAIVER PROGRAM

International medical graduate physicians completing their medical training (residency or fellowship) in the U.S. on a J-1 Visa are eligible to remain in the country after the conclusion of their training if they agree to provide service for a period of three years in an underserved area. Otherwise, their J-1 Visa requires them to return to their home country immediately upon completion of their training. State health departments must recommend to the federal government that the service of these physicians is needed and request that the federal government waive the requirement to return to their home country. If granted a waiver, the health department must monitor each physician's service for the three-year commitment. DPHD administers this program in Pennsylvania and facilitates the placement of international primary care and specialty physicians in underserved areas throughout the commonwealth. Approximately 100 physicians provide care through this program annually.

COMMUNITY-BASED HEALTH CARE GRANT PROGRAM

This annual competitive grant program provides funding to non-profit community-based primary health centers located in, or serving, medically underserved communities to expand or improve primary and preventive health services. Grant funding ranges from \$50,000 to \$500,000 over a period of two years and includes the option to use funding to hire primary care providers, dental providers, and behavioral and mental health providers. This program began in 2013 with 40 community-based health centers receiving grants, many of which are hiring providers with grant funds.

In addition to these programs, DPHD provides grant funding to several partner organizations to administer programs designed to increase the number of primary care providers in Pennsylvania. These include the Pennsylvania Association of Community Health Centers which administers the Pennsylvania Primary Care Career Center to assist health centers in recruiting providers; the Pennsylvania Academy of Family Physicians which administers the Primary Care Residency Expansion Program to increase the opportunities for primary care physicians to complete their residency training in the commonwealth; and the Penn State College of Medicine's Area Health Education Centers (AHEC) program which provides training opportunities for medical and health professions students in rural and underserved areas of the commonwealth.

For more information on these and other programs administered by the Pennsylvania Department of Health, Bureau of Health Planning, call 717-772-5298 or visit www.portal.state.pa.us/portal/server.pt/community/primary_care_resources/14194.

Urban and Rural Health:

A Patient's Perspective on Receiving High Quality Care Close to Home

By: Erin Butters

I spent the first 27 years of my life in the Boston, Massachusetts area, where I had almost immediate access to some of the best and brightest medical professionals, using the latest technology.

I had a fairly uneventful life, medically speaking, barring arthroscopic surgery on my knee following a high school sports injury. I always felt like I received excellent medical care, but I never really felt like the doctors and other medical staff got to know me beyond my medical needs or concerns.

After moving to Wellsboro, Pennsylvania 10 years ago, my medical needs changed. As a patient at the Guthrie Heath Systems Clinic, I have had precancerous cells removed, suffered through years of allergy shots, and delivered two daughters—the second of whom came into this world under difficult circumstances.

In 2009, I was pregnant and going to the Guthrie Clinic in Wellsboro for checkups, where I would routinely see different doctors in order to feel comfortable regardless of which one would deliver my baby. I realized how incredibly fortunate my husband and I were to be able to develop a relationship with each of the physicians at the Guthrie Clinic when I spoke to a friend about my experiences here. A resident of Brooklyn, New York expecting her first child, my friend told me she would likely never meet the doctor who would deliver her daughter before her delivery day. The fact that I knew the Guthrie doctors would prove to be incredibly important when my daughter was born.

Two days before my due date, my dad passed away unexpectedly. The stress of the situation sent me into labor, and at about 4:00 a.m., we headed to the OB unit at nearby Soldiers & Sailors Memorial Hospital. I was given medication to manage my anxiety and blood pressure, and my daughter was monitored closely. I was relieved to see many of the same faces in the OB unit who were there when my first daughter was born—including the same Guthrie doctor. All of this made an incredibly stressful situation a little less overwhelming.

After an intense and painful labor, my daughter was born ... complete with my dad's red hair. The birth had been stressful for her as well; it took a full minute before she took her first breath. When I finally heard her cry, I felt relief and was hopeful there wouldn't be any more major hurdles for the day. We got to cuddle and take the requisite pictures before she was whisked off for a bath and follow-up tests. I started to make my way into the bathroom to shower.

But something was most certainly not right.



Erin Butters and her family: step-daughter, Jordan (17); husband, James; daughter, Emery (4); Erin Butters; daughter, Rowan (6); and standing is step-daughter Kaeli (15)

When I stood up, blood began pouring down my legs, and it didn't take long before I was standing in a pool of blood. My panicked husband called the nurses and doctor, who quickly got me back into bed. It felt like mere seconds for the entire OB team to be in my room trying to keep me conscious while working to find and stop the source of my bleeding. My doctor explained that the best emergency OB surgeon in town was on her way—a clinically trained military physician with decades of experience.

I was prepped for surgery while my doctor talked me through what to expect. Though I was drifting in and out of consciousness, I asked her what the worst case scenario was. I was grateful when she didn't mention bleeding to death. But I knew her, I trusted her, so I wasn't worried. Following a successful surgery, four blood transfusions, and three days in the ICU, I was as good as new ... or at least on the mend.

I suppose another doctor walking into that situation could have handled it just as successfully, but my relationship with my doctor and the nurses made my situation better. I wasn't just a patient to them. I was a woman, a mom, a wife, and someone they knew. I trusted my doctor and that OB unit staff, and they kept me from fearing the worst.

To this day, my daughters, now four and six, receive their medical care at the same Guthrie Clinic where I have gotten such excellent care. I've found that though rural physicians may occasionally need to depend on technology for access and information, they have no fewer resources than their urban counterparts. Rural medicine, as I understand it, depends on the resiliency and creativity of the individual health care provider. I often encounter medical students on rotation in Wellsboro during an

office visit, and I have learned how important it is for future physicians to learn from rural physicians. Not only does the experience encourage students to consider rural medicine, it also creates a partnership—students bring knowledge of the latest and greatest from their own classrooms and previous rotations, and our community doctors can share their passion and experiences. This collegial partnership adds to the level of excellence of rural medicine.

While I admit it may be inconvenient at times to travel an hour or two for specialty services, I know my emergency needs are taken care of close to home. When I first moved to Wellsboro, I thought a smaller population would offer fewer resources. I learned instead that fewer resources don't translate into a lack of quality. What you lose in local access to medical services available in an urban or suburban setting, you gain in trusting and caring relationships with qualified medical staffers who keep you and your family healthy. You see them at the ball fields and community events. They become a permanent part of your support system.

I don't anticipate relocating to an urban setting, but if I do, my health care expectations will be much higher because of my experiences here in rural Pennsylvania.

Erin Butters shared her story with members of the Pennsylvania General Assembly during the 2014 Rural Legislative Briefing coordinated by PORH and other rural partners. She graciously agreed to have her experiences shared here.

Celebrate National Rural Health Day!

November 20, 2014

National Rural Health Day, established by the National Organization of State Offices of Rural Health, is the day to showcase Rural America and highlight the efforts of rural advocates in addressing the unique health care needs of rural communities.



For more information, visit celebratepowerofrural.org or call the Pennsylvania Office of Rural Health at 814-863-8214.



Upcoming Events

October 2, 2014

A View to the Future: Policy and Practice Impacts of Community and Public Health

Penn Stater Hotel and Conference Center, State College, PA
Sponsored by the Pennsylvania Public Health Association and the Pennsylvania Office of Rural Health

For more information, visit www.porh.psu.edu or call 814-863-8214.

October 8, 2014

Let's Move Pennsylvania

Penn Stater Conference Center Hotel, State College, PA
Sponsored by Better Kid Care – Penn State Extension

For more information, visit extension.psu.edu/youth/betterkidcare/events/lets-move.

October 23-25, 2014

27th Annual East Coast Migrant Stream Forum

Sheraton Station Square, Pittsburgh, PA
Sponsored by the North Carolina Community Health Center Association, the Pennsylvania Office of Rural Health, and other partners

For more information, visit www.ncchca.org/events/event_details.asp?id=433525.

May 5, 2015

Pennsylvania Community Health Worker Symposium

Penn Stater Hotel and Conference Center, State College, PA
Sponsored by the Pennsylvania Office of Rural Health, the Eastcentral Pennsylvania Area Health Education Center, and other partners

For more information, call 814-863-8214.

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