The technology and models of care behind Children’s neuro-oncology program

Also inside:
Children’s named to “America’s Best Children’s Hospitals”
Quality standards in pediatric health care
Children’s Hospitals and Clinics of Minnesota — ranked as one of the top 30 Children’s Hospitals in the U.S. (see page 8) — treats more than half of all Minnesota children with cancer, with outcomes comparable to and better than national norms. Each year, Children’s serves around 200 new patients with cancer and blood disorders. Our mission is to help these patients live life as vigorously and boldly as possible.

Among our nationally recognized programs is our Stoplight program, which keeps children active from the moment their cancer care begins. The goal of the program is to help them build resilience that can help them bounce back from cancer treatments and quickly resume daily activities.

Our feature story in this issue of Children’s Practice explores another component of Children’s hematology/oncology program. It includes a look at intraoperative MRI — a remarkable new technology available at both of our hospital campuses and shared by only a handful of pediatric hospitals in the world. In addition, the excellent work of our neuro-oncology team, led by Anne Bendel, MD, is another example of next generation care that contributes to our outstanding outcomes.

This issue includes the latest installments from regular contributors Peter Dehnel, MD, Children’s chief of staff, and Mary Braddock, MD, MPH, Children’s senior director of child health policy. Dr. Braddock’s policy column offers a thought-provoking look at possible quality standards in pediatric health care. Dr. Dehnel’s advocacy column focuses on the extensive work — even with recent anti-smoking legislation — that remains if we are to reduce teen tobacco use.

Thank you to those who have taken time to send me your thoughtful feedback about Children’s Practice. Your comments have confirmed the value of the magazine and are shaping our ongoing efforts to enhance it.

If you have comments or suggestions, please contact me at phil.kibort@childrensmn.org or (612) 813-6165.

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On the cover: Six-year-old Daniel Wilke proudly shows the “before” and “after” photos of his brain tumor, which was removed at Children’s of Minnesota.
Central nervous system (CNS) tumors are the second most common cancer in children, making up as much as 20 percent of childhood cancers. Last year, Children’s Hospitals and Clinics of Minnesota provided care for 55 new CNS tumor patients and annually cares for nearly three-fourths of pediatric patients hospitalized for cancer and blood disorders in the Twin Cities metropolitan area.

Despite the delicate and dangerous nature of these tumors, the care provided by Children’s of Minnesota has proven to be highly successful, with outcomes that compare very favorably to national norms.

To achieve these outcomes, Children’s of Minnesota relies on innovative, high-technology procedures — those performed in only a handful of pediatric hospitals in the world. In addition, it complements these advanced technologies with an equally important and effective “high touch,” post-operative treatment program. This program, which is based on the principles of communication and collaboration, is designed to minimize the complications that can arise as a result of the measures used to treat CNS tumors.

**Intraoperative MRI reveals a new level of precision**

In the effort to cure CNS tumor patients, Children’s of Minnesota has access to one of the world’s most advanced and promising tools: intraoperative MRI.
Through a partnership with Abbott Northwestern Hospital and United Hospital, this technology is available at Children’s hospitals in both Minneapolis and St. Paul. Developed within the last five years, intraoperative MRI is a real-time, computer-assisted surgical navigation tool. It allows surgeons to pinpoint the location of tumors and lesions, including those previously considered inoperable.

“Intraoperative MRI offers unprecedented visualization of how completely a lesion or tumor resection has been accomplished,” said Mahmoud Nagib, MD, a neurosurgeon at Neurosurgical Associates and member of the professional staff at Children’s. “It allows for a more precise surgical corridor to the lesion.”

The extreme precision of the intraoperative MRI greatly reduces the chances that residual tumor tissue will go undetected during surgery. The result is fewer subsequent surgeries and reduced chances for post-operative deficits.

“You don’t have the luxury — as you sometimes have in other parts of the body — of taking extra tissue around a brain tumor because it could cause a neurological deficit,” explained Jerone Kennedy, MD, a neurosurgeon at United Neurosurgery Associates and a Children’s professional staff member. “Now, the intraoperative MRI allows us to identify and safely remove residual tumor tissue without having to perform a second surgery.”

**Post-operative benefits**

“The detailed information we learn as part of the intraoperative MRI procedure gives my colleagues in neuro-oncology what they need to identify an appropriate course of treatment for patients,” added Nagib, noting that advances in the intraoperative MRI will soon make it possible to visualize the brain tracks that carry sensations from the brain to the spinal cord.

The benefits of this new technology for children include smaller incisions and reduced bone flap removal. These less invasive neurosurgical procedures contribute to shorter recovery and fewer short- and long-term complications.
“Most importantly, the more complete the resection, the more effective post-operative therapies like radiation and chemotherapy generally are,” Kennedy said. “We believe these patients will have a longer period of time without a tumor recurrence — if they have one at all — and, therefore, enjoy a better quality of life.”

Minimizing side effects; maximizing potential

The removal or elimination of a CNS tumor — made possible through technologies such as intraoperative MRI — is certainly cause for celebration for children and their families. But it is often only the beginning of an equally critical post-operative treatment process. The drastic measures frequently required to cure patients, combined with the ultra-sensitive nature of the central nervous system, mean a high percentage of children have short- and long-term issues and complications that must be addressed.

“We want to cure children, but we don’t want to leave them with potentially devastating side effects,” said Anne Bendel, MD, a pediatric hematology-oncology specialist and leader of the Children’s of Minnesota neuro-oncology program. “Our goal is to maximize the cognitive and physical potential of the patient while we minimize the effects of treatment on their quality of life.”

The key to doing that, said Bendel, is a comprehensive, coordinated, and collaborative model of care. It is a model that has been used at Children’s for many years and one that has become vital to Children’s strong outcomes.

A plan of action

At the start of each patient’s post-treatment care, children and their families receive a written plan which spells out the neuro-oncology team’s findings, recommendations, and plan of care for the next several years. Integral to this plan is a series of appointments in the multi-disciplinary neuro-oncology clinic.

This clinic meets once or twice a month on the Children’s - Minneapolis and Children’s - St. Paul campuses. It includes participation by the oncologist, neurosurgeon, neurologist, physical therapist, endocrinologist, social worker, pharmacist, neuro-radiologist, and neuro-psychologist. Patients, who spend an afternoon in the clinic, are evaluated by each of these subspecialists during a single visit.

Once a tumor has been removed or eliminated, most children and their families have been through countless appointments, surgeries, and treatments. Another year or more of meetings with specialists — from endocrinologists and neuro-oncologists to ophthalmologists and physical therapists — is something few are eager to undertake.

“Many children come from a long distance, so coming to one place to see all of the specialists is convenient,” said Bendel. “That convenience is an important part of the success of our program because it helps ensure full participation from patients and their families.”

Dialogue, collaboration drive success

Even when families do follow all aspects of a post-operative plan with several independent specialists, there are potentially critical opportunities for...
“Children’s earned the highest marks possible for very low mortality following removal of malignant brain tumors.”*


communication that are missed. “Because communication among the individual outside specialists isn’t done face-to-face, each patient evaluation is not conducted with a shared knowledge of the patient’s unique situation and history,” Bendel explained.

The difference at Children’s is that this is a dialogue that Bendel and the rest of the interdisciplinary neuro-oncology team of specialists have regularly. Instead of exchanging information remotely, the team of specialists sits face-to-face immediately before and after each

Intraoperative MRI provides physicians with an unprecedented ability to pinpoint the location of tumors and lesions.
patient's monthly visit. There they discuss a patient's progress as well as any concerns and findings from the day's appointment.

“We’re constantly collaborating and can help each other identify issues that independently could easily be overlooked,” said Bendel. “For example, my knowledge — shared with the ophthalmologist — that a patient had a stroke during surgery may be an important clue to identifying and resolving a patient’s vision problem before it becomes serious.”

**High marks from all**

The opportunity for dialogue also extends to patient families.

“Because the clinic offers a longer appointment with families, it allows more time for us to educate them. As a result, families inquire more and more with questions about things that haven’t arisen in previous discussions,” Bendel explained.

The model has received outstanding marks from families — Bendel and her team have earned a 98 percent satisfaction score from patient families. It also has been well received by members of the neuro-oncology team.

“We have learned a lot from each other — so much so that we are beginning to identify issues outside of our own areas of expertise,” said Bendel. “It is very satisfying to both the patients and providers to have the most experienced professionals looking at a patient in a collaborative way. We consider that next generation care and we are big believers in it.”

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*For referral, consultation, or more information about Children’s neuro-oncology program or the hematology/oncology program, call (612) 813-5940 or (651) 220-6732.*

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“We wouldn’t go anywhere else.”

“This is the best place you never want to be,” said Jennifer Wirz of Children’s and its neuro-oncology program. Wirz carries in her purse an MRI image of her son Daniel’s first brain tumor. “When I’m having a bad day, it reminds me that life could be so much worse.”

The image of the goose-egg-sized brain tumor was taken last September. At the time, Wirz says she thought they were being sent to Children’s to set up end-of-life care. “But no one at Children’s has ever talked about anything other than saving Daniel’s life.”

After the tumor was successfully removed last year using traditional surgical methods, a second smaller tumor developed. That tumor also was successfully removed — this time, through the use of intraoperative MRI.

“We were thrilled with the outcome of Daniel’s first surgery, but the fact that surgeons got such an advanced look at his second tumor (using intraoperative MRI) was simply amazing.”

Daniel and his parents, who drive nearly 90 minutes each way to and from Children’s to meet with the Children’s neuro-oncology team, say the effort is well worth it.

“It’s wonderful that on Dr. (Anne) Bendel’s team there are so many people working together on Daniel’s treatment,” said Wirz. “We wouldn’t go anywhere else.”
“Our ranking in *U.S. News & World Report* is a direct reflection of our institutional commitment to advance the quality and safety of care for children.”

- Alan L. Goldbloom, MD, president and CEO of Children’s

**Children’s named to “America’s Best Children’s Hospitals”**

- Children’s earned the highest marks possible for very low mortality following removal of malignant brain tumors;
- Children’s was one of only four hospitals awarded the highest marks possible for its palliative care and pain management program;
- Among the 30 hospitals, Children’s had the second-highest ratio of registered nurses to patients and was recognized for its designation as a Magnet hospital by the American Nurses Credentialing Center.

The 2007 rankings (available online at [www.health.usnews.com/pediatrics](http://www.health.usnews.com/pediatrics)) reflect advances in the magazine’s methodology for determining the highest quality among pediatric hospitals. While previous rankings used only subjective criteria — reputation among surveyed physicians — this year’s edition expands to include verifiable data that measures quality in pediatric care.

This is the third major national recognition for Children’s in less than a year. Children’s again was ranked among the top 7 U.S. pediatric hospitals in a landmark survey of quality and patient safety released in September 2007 by the respected Leapfrog Group. In October 2006, Children’s was awarded Magnet designation in recognition of excellence in nursing.
Emergencies happen far less frequently in children than in adults. Is your team ready to respond to the next pediatric or neonatal emergency? The experienced staff at Children’s of Minnesota want to help ensure your team is prepared for pediatric or neonatal emergencies that may arise. We’ll even bring the training to you.

The Kohl’s Mobile Simulation Center uses computerized infant- and child-size mannequins, along with sights and sounds, to reproduce a clinical environment that provides the same physical challenges and mental stressors that would occur in a real emergency. The scenarios are customized to fit the experience of the participants, whether they are novice or expert practitioners.

Debriefing is key to the simulation’s effectiveness and is facilitated by trained instructors. The team reviews every stage of the crisis to identify what went well and where improvements can be made. Debriefing helps participants reflect on their experiences, share significant insights, and apply lessons learned to the real-life setting.

Simulation training enables teams to increase patient safety by understanding each others’ roles and learning to communicate in a crisis situation.

Three courses are available:
- Pediatric Resuscitation Team Training
- Pediatric Rapid Response Team Training
- Resuscitation and Stabilization of the Critically Ill Neonate

Team registration is required. Teams typically include physicians, advanced practice nurses, nurses, pharmacists, respiratory care practitioners, or any other staff member the hospital deploys in an emergency situation.

To learn more about the simulation program at Children’s, visit us online at www.childrensmn.org/simcenter. There you’ll find videos about simulation training, detailed course description, and registration information. For more information, contact Thomas Hellmich, MD, MBA, medical director, or Karen Mathias, RN, MSN, APRN, director.
Children’s to transform hospitals into next-generation facilities

Transforming hospitals into next-generation facilities begins in 2007 at Children’s Hospitals and Clinics of Minnesota. At the St. Paul and Minneapolis campuses, significant changes are proposed so that the hospitals can provide the safest, most advanced pediatric care possible.

These changes in the next three to five years will result in the most significant campus development since Children’s current facilities were built. The improvements will embody Children’s emphasis on family-centered care, offering a comfortable inviting environment for children and families. All hospital rooms will be private. Public spaces will encourage discovery and learning.

Physicians and other health care providers, patients, and families have been active participants on numerous planning teams, giving their ideas and advice for the proposed designs. “Green” practices in healthy and environmentally sustainable design, construction, and maintenance are being incorporated. In addition, design principles will reflect Children’s work to remove waste and unnecessary complexity from health care processes, a program called Lean.

Children’s planning also involved the review of leading examples of innovation hospital design from around the country.

Expansion plan highlights

CHILDREN’S – MINNEAPOLIS
- New ambulatory care center, with family and visitor parking
- New operating rooms
- New neonatal intensive care unit
- New pediatric intensive care unit
- New emergency department
- Ronald McDonald House within the hospital
- Single rooms with private baths and sleep-in space for parents

CHILDREN’S – ST. PAUL
- New operating rooms with appropriate pre- and post-operative space
- Expanded emergency department
- Relocation of pediatric epilepsy unit to Children’s (now housed at United Hospital)
- Green space for families and employees
- Enlarged private rooms with private bathrooms

At left: Preliminary architect’s rendering of the St. Paul campus (top) and the Minneapolis campus (bottom).

To provide comments, contact Phillip Kibort, MD, vice president of medical affairs and chief medical officer, (612) 813-6165, phil.kibort@childrensmn.org.
With the passage of the “Freedom to Breathe” legislation this spring, we all will, literally, be able to take a breath of fresher air. This is especially good news for our children and teens, who will not be subjected to the adverse effects of tobacco smoke at work or in other public places. In the long run, it is likely to help reduce their likelihood of starting tobacco use.

While this is a very good step in the right direction, much work remains to reduce tobacco use by teens. Twelve- to 19-year-olds are still the most likely age group to initiate tobacco use. A 2005 study revealed that 54 percent of high school students have smoked at least one cigarette during their teenage years, and 28 percent of high school seniors designate themselves as “current smokers.” Young adults — 18- to 24-year-olds — have a significantly higher rate of tobacco use than the 21 percent average for all adults.

Why is tobacco use still so prevalent? The answer clearly points to the $15 billion dollars that the U.S. tobacco industry spends annually to promote the use of its products. The movie industry is a particularly effective vehicle for tobacco companies to promote their products to teenagers.

Tobacco “product placements” and the depiction of tobacco use in movies has risen significantly since the early 1990s. According to the American Lung Association’s Sacramento office, 66 percent of the 50 top-grossing films in 2004 and 2005, contained depictions of smoking, with an average frequency of 12.8 incidents per hour.

This statistic is particularly disconcerting in light of the fact that teenagers who see a favorite actor smoking in only three movies are twice as likely to initiate tobacco use.

A call to action

Opportunities for health care professionals to decrease future tobacco use by our young patients exist in at least five areas:

1. Encourage families to adopt a “smoke-free home pledge.” Restricting tobacco smoke from homes and cars will go a long way toward neutralizing the pro-smoking influence and childhood morbidity associated with second-hand smoke exposure.

2. Identify effective tobacco-cessation programs for parents. If existing programs are not feasible or effective, consider developing a cessation program within your clinic.

3. Inquire about tobacco use and exposure at every opportunity. Motivate (without alienating) families to reduce tobacco use and exposure.

4. Incorporate prevention messages into all well-child visits. Five- and six-year-olds can clearly identify tobacco-related characters and product logos. Give them a balancing message at an early age.

5. Contact the Motion Picture Association of America (MPAA). Encourage the MPAA to put any film that contains images of smoking into the “R” rating category.

Preventing tobacco use is an intervention that continues to be important for everyone who cares about children and teens. Be consistent in your approach and you will benefit your patients long after they “graduate” into the world of adult medicine.

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Get involved with discussion on quality standards in pediatric health care

by Mary Braddock, MD, MPH

Last year, Children’s Hospitals and Clinics of Minnesota published its first comprehensive Outcomes Report*. In this project, we sifted through reams of data about Children’s health care outcomes, with the goal of helping families, referring physicians, payers, and policy makers make informed decisions about the quality and effectiveness of our programs.

Ironically, this project foreshadowed an emerging push by the federal government for quality measurements in pediatric health care. To provide greater accountability for its approximately $186 billion annual investment in pediatric health care through Medicaid and the State Children’s Health Insurance Program (SCHIP), Congress recently authored and introduced the Children’s Health Care Quality Act, which would provide $100 million over five years to help the Centers for Medicare and Medicaid Services (CMS) develop, test, and promote measures for pediatric health care.

As this article went to press, portions of the Children’s Health Care Quality Act had been included in both the Senate and House-passed SCHIP bills. In the big picture, it’s hard to disagree with quality
“Demands for quality and value must be balanced against the need for families to feel confident their child is getting the best care available.”

measures for children’s health care. However, there are several reasons why pediatric physicians and other professionals should be involved in developing the fine print. These include:

**Going beyond broad-based numbers.** Many past measurement efforts have focused on simple, high-level metrics, such as mortality rates or the number of preventive visits received. However, the growing emphasis on quality requires a new approach, one that more accurately reflects actual clinical outcomes that result from care delivered to the patient.

**Differentiating adults from kids.** Among older adults, there is a relatively narrow range of chronic conditions — such as high blood pressure or heart disease — that affect most people to varying degrees. Conversely, the majority of children are healthy, but the ones who do get sick exhibit an extraordinary range of medical conditions. That makes it more difficult for pediatric health care professionals to confidently identify “chronic conditions” that should be monitored and reported as indicators of overall pediatric health care quality.

**Developing comparative data sets.** In pediatric health care, there are a number of databases that track care outcomes. But none of the current systems are designed to illustrate how hospitals or clinics perform in their delivery of comparable services.

As written, the Children's Health Care Quality Act promises that CMS will seek input on appropriate measures from national pediatric organizations, consumers of children's health services, and others with expertise in pediatric quality. As a referring physician, you know that increased payer demands for quality and value must be balanced against the need for families to feel confident their child is getting the best care available. By participating in the discussion, you can help build a sound, evidence-based system that will make it easier for all parties to make informed choices about pediatric health.

Children's has launched an advocacy and policy section on our Web site. This site provides tips and opportunities for getting involved in shaping this important pediatric health care policy as well as other policies vital to improving the health and well-being of children.

* The Children’s Outcomes Report is available on www.childrensmn.org. Click on “For Health Professionals” and look under “Resource Materials.”

Mary Braddock, MD, MPH, is senior director of child health policy and medical director of the Center for Care Innovation and Research at Children’s of Minnesota. She can be reached at mary.braddock@childrensmn.org or at (612) 813-6027.
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Children’s – St. Paul
Hospital and specialty clinics
345 North Smith Avenue
St. Paul, MN 55102
(651) 220-6000

Children’s Clinics – Woodwinds
Specialty and rehabilitation clinics
1825 Woodwinds Drive
Woodbury, MN 55125
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Children’s – Maple Grove
Rehabilitation clinic
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Rehabilitation clinic
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Children’s mission:
Children’s Hospitals and Clinics of Minnesota champions the special health needs of children and their families. We are committed to improving children’s health by providing high-quality, family-centered pediatric services. We advance these efforts through research and education.

Children’s vision:
Become one of the nation’s best pediatric providers, accessible to all children.

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EDUCATIONAL OPPORTUNITIES

Pandemic Influenza in Pediatrics: Justice, Scarc Resource, and Tough Decisions
Westgate Pediatric Ethics Forum 2007
Friday, Nov. 16, 2007
Noon to 4 p.m.
Children’s – Minneapolis campus

2nd Annual Pediatric Emergency Medicine Conference
February 29, 2008
7:30 a.m. to 5 p.m.
Minnesota History Center, St. Paul

Pediatric Surgery Conference
May 2, 2008
7:30 a.m. to 5 p.m.
Minnesota History Center, St. Paul

Annual Spring Pediatric Update
Potpourri of Psychopharmacology Use
May 8, 2008
John Nassef Medical Center
Children’s – St. Paul campus

5th Annual National Pediatric Telehealth Conference
September 25-27, 2008
Hilton MSP Airport, Bloomington

Information about these conferences and other upcoming events will be posted on Children’s Web site, www.childrensmn.org.

Online Grand Rounds
With a library of nearly 100 presentations, Children’s of Minnesota offers Grand Rounds online.
To view the presentations, follow these easy steps:
1. Log on to www.childrensmn.org.
2. Choose “Grand Rounds” under “For Health Professionals.”
3. New users will first need to register. Once registered, all you have to do is choose the presentation.

Children’s Hospitals and Clinics of Minnesota
Delivering Next Generation Care