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Editor's Note:
St. Louis Children's Hospital, one of the five affiliated institutions in the Washington University Medical Center, has been serving the St. Louis Community for 100 years. The School of Medicine affiliated with the Hospital in 1910 and since then has played an important part in pediatric patient care and research. The stories in this issue of Outlook examine a few of the areas of pediatric medicine in honor of this 100 year anniversary.

On the cover:
Housestaff of Children's Hospital in 1919. W. McKim Marriot, M.D., (second) chairman of the Department of Pediatrics, is in the front row, third from the left. Women were permitted to join the housestaff in 1918. See story on page one.

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Outlook Magazine

St. Louis Children's Hospital: 100 Years of Service
A quiet revolution in childhood cancer
After 20 months, Teddy goes home

Pediatric Rehabilitation: A new, successful service
Reye Syndrome: Still a mystery
Siamese Twins: Unique challenge for pediatric surgeons

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One hundred years ago, on October 29, 1879, St. Louis Children's Hospital (SLCH) opened its doors to patients for the first time. Appoline A. Blair, Mary W. McKittrick, Caroline B. Treat, Margaret H. DeWolf, Rebecca Webb, Cherrell W. Parker, Virginia E. Stevenson, and M. Louise Norris were specifically named on the hospital's certificate of incorporation, issued by the Circuit Court of St. Louis on May 6 of that year. This document noted: "They are, therefore, hereby declared a body politic and corporate . . . with all the powers and privileges, and immunities granted in the Act above named . . . ."

The grand legal language of this certificate was a contrast to the modest nature of the hospital's first year in a small rented house at 2845 Franklin Avenue in downtown St. Louis. The annual reports reveal that the number of patients admitted on the first day was two, the bed capacity was 43. The operating budget for this first year was $2,611, raised from annual subscriptions of one dollar to $100. Such figures can tell only a part of SLCH's history. To understand its significance for the children of St. Louis, and for the medical community, it is important to look at the circumstances of its founding, and at the founders themselves.

The small rented house on Franklin Street embodied a new idea for the 19th century: that children should receive a special kind of medical care, not available in general hospitals. The first American children's hospital was founded in Philadelphia by 1855; a century earlier such hospitals had been established in major European cities. The idea of children's hospitals was closely related to both humanitarian concern for the young and to the development of pediatrics as a medical specialty.

As the certificate of incorporation indicates, women played a leading role in founding St. Louis Children's Hospital. This was true not only for the hospital in St. Louis, but for institutions serving children in other large American cities. Women in the late 19th century often felt a special responsibility for what was then called "childsaving." This involved not only founding or supporting hospitals but starting orphanages, kindergartens and daycare centers as well.

This humanitarian concern was part of a new attitude toward childhood which developed during the 19th century. It was expressed through the establishment of special institutions, both educational and medical, to serve children's needs. There was a new realization that children were not just miniature adults but unique and growing organisms with distinct needs for protection and care. This is what the French historian Phillippe Aries has termed the "discovery of childhood."

The German kindergarten, so successfully transplanted to America and supported in large part by women, was one expression of this discovery. Miss Susan Blow, whose work in St. Louis led to the establishment of the kindergarten in the public school system, was among the first subscribers to St. Louis Children's Hospital. This is not surprising, since both the kindergarten and the Children's Hospital shared the idea that children were worthy of special attention and care.

Women's humanitarian activities on behalf of children in schools, hospitals, and other institutions also reflected the belief that women had a particular, innate ability in any enterprise involving the young. These charitable or professional interests were seen as natural extensions of women's homemaking and childrearing talents, what was called "women's sphere." The corresponding male interests were supposed to be in the areas of business or professional activity. While 19th century men were sometimes active in charities, their participation was understood as subsidiary to their other responsibilities.

For women, such as the founders of St. Louis Children's Hospital, humanitarian concerns were a career in themselves at a time when few women were permitted to enter professions or business. A striking characteristic of the Hospital managers was
Children's Hospital

Mrs. Appoline Blair, founder and first president (1879-83), SLCH Board of Managers.

"The moral tone of the wards is... not very elevated, and it is wrong to expose the children to moral contamination in order to obtain a rather uncertain physical result..."

Jacobi's references to "moral contamination" and an "uncertain physical result" for children on general wards indicated the low status of the 19th century hospital. It was generally a place of last resort for the most desperate of citizens: the poor and the homeless. Those who could possibly afford it chose to receive medical care, including surgery, at home. By definition, then, a 19th century children's hospital was founded to serve the poor. Only in the 20th century did the hospital lose its "pesthole" image; this was due to the rise of scientific, effective medicine.

Nonetheless, pediatrics developed rapidly during the late 19th century, in large part be-
cause of the new humanitarian interest in children. Jacobi and other physicians saw the establishment of children’s hospitals as necessary for both better medical care and a better environment for young patients. In 1879, the year St. Louis Children’s Hospital opened, the American Medical Association recognized pediatrics as a special branch of medicine with the formation of a section on the diseases of children.

While doctors did not gain significant insights into pediatric biochemistry and bacteriology until the turn of the century, between 1860 and 1900 children's hospitals were established in American cities from New York to San Francisco. These institutions were an indication of pediatrics' claim to public legitimacy and concern. A tender concern for the young was far easier for most people to understand than medical technology, and support for children's hospitals in St. Louis and elsewhere was emotional and enthusiastic.

St. Louis physicians shared the humanitarian concerns of other citizens; they were well aware of the need for a children's hospital in their city. James Kingsley, M.D., of St. Louis published a series of letters in the Globe-Democrat during 1878, discussing his observations of European medical facilities compared to those at home. During that year he wrote:

It is a well-known fact that the infant mortality in the City of St. Louis is something appalling, enormous... yet in St. Louis there is no children's hospital; no provisions for saving the lives of these little ones for whom Christ had such a tender care...

"When one comes to think that nearly half of all children brought into existence die before they arrive at the age of 5 years, the necessity for children's hospitals, from a humanitarian point of view, is readily understood... I presume it would be difficult to find anywhere this side of the water a city one-fourth the size of St. Louis without a children's hospital...

Thus, the medical community, as well as public-spirited citizens, stressed the need for a children's hospital on humanitarian grounds. This is significant because Kingsley and his colleagues realized that a children's hospital in itself could not cure the enormous health problems of the time.

Indeed, the term "incurable" could be applied to most diseases, both chronic and infectious, because antibiotics, transplants, and methods of fluid replacement did not then exist. A simple gastrointestinal upset could be, and often was, fatal for young children. Such "minor" childhood diseases as scarlet fever, measles, and chickenpox had mortality rates of up to 50 percent.

Effective immunization for diphtheria and tetanus did not then exist. In addition, the public health conditions of large American cities, including St. Louis, were appalling — and especially deadly to the very young. Food and water were often tainted; sewage and garbage disposal were minimal. In 1879, for example, the St. Louis City Board of Health admitted in its annual report published a list of miscellaneous donations.

Mr. Hugh McKittrick, 2nd president, SLCH Board of Managers (1883-1907).
report that it could not estimate the number of children who died during the previous year.

However, there is no reason to dispute Kingsley’s figure of a 50 percent mortality for children under five years of age. Much of the 20th century decline in child mortality can be traced to better public health measures, as well as effective immunization and treatment for infectious disease.

With this background the problems St. Louis Children’s Hospital managers had to face in 1879 are obvious. Even a hospital conceived as a special place to care for the young had to overcome the negative image of the very word; people in the 19th century often felt, quite rightly, that hospitals were dangerous places. The reminiscences of Miss Virginia Stevenson, a charter member of the Board of Managers, are illuminating: “The name St. Louis Children’s Hospital was sufficiently all-embracing and noncommittal, therefore it was adopted. The question was money. We decided that each woman should pledge herself to raise at least $200 a year . . . It was a pleasure for me to visit my friends and acquaintances for the annual $5 subscriptions . . . It was a little difficult at first, to fill our home. We opened with one, a crippled boy named Bennie . . .”

Her reference to the difficulty of filling “our home” is significant. It reveals the lack of enthusiasm most people had for hospitals, and also shows that the management of a children’s hospital in the late 19th century was more domestic than scientific in nature.

Early donations to St. Louis Children’s Hospital included bed sheets, towels, wash cups, mops as well as hobby horses, ice cream, books and toys. These show both the practical housekeeping aspects of the hospital, and the special needs of child patients for pleasure and play.

While women comprised the Board of Managers, they were well aware of the talents St. Louis men could bring to bear on their new enterprise. They chose members of a “gentleman’s advisory board” from among their friends and relatives, many of whom were prominent citizens. While the women felt confident in attending to the caretaking and housekeeping aspects of the hospital, they looked to the men for financial and legal advice.

This is obvious from the hospital’s first annual report of 1880: “… the gentlemen of the advisory board strongly advised the managers to purchase (rather than rent) a house, as the possession of a building would give the institution a better position as a settled charity . . . the building (on Franklin Street) was purchased for $4500 . . .”

While the annual subscriptions to the hospital, used for running expenses, were often modest (from $1 to $5), the building fund donations ranged up to $500. By 1884 prominent donors included Robert Brooking, Robert Barnes, Erastus Wells, Augustus Busch, and Hugh McKittrick. Thus from its inception, St. Louis Children’s Hospital was able to benefit from the talents of both men and women. In addition, children themselves made small gifts to the hospital from its first year in 1880 the primary class of Mary Institute gave $7.80; such donations have continued to be important at St. Louis Children’s Hospital to this day.

The first annual report listed a staff of nine physicians and surgeons. Their services were “gratuitously rendered,” a common practice in urban voluntary hospitals. The hospital’s annual reports indicate that the medical staff through most of the 19th century were homeopaths, members of a medical sect which believed in treating patients with very small doses of drugs. This sect was popular from the 1840’s until the 20th century triumph of scientific medicine.

At the time Children’s Hospital was founded, regular physicians still resorted to heroic or painful procedures such as purging and bleeding. The major tenet of homeopathy, the careful administration of highly diluted drugs, seemed especially appropriate for children.

One of the hospital’s original managers noted that it was a concern with the large doses of medicine given by “regular” physicians which led mothers in St. Louis to choose homeopath as the medical staff for Children’s Hospital. Nonetheless, homeopaths often practiced surgery and did other procedures similar to those of their “regular” colleagues. Surgery was listed among the hospital’s services at an early date; most operations were minor procedures on eyes, ears, infections, and bones.

These limited surgical services reflected the general limitations of all 19th century medical care, for children or adults. The means of surgical or medical intervention were few.

Much of the care at St. Louis Children’s Hospital consisted of careful nursing, supervised by physicians. A “staff of nurses” was not mentioned in the annual reports until 1885. The by-laws indicate that they were probably not highly trained; a basic requirement by 1886 was simply that “nurses must be able to read and write.”

Admission to Children’s Hospital was restricted in the early days. The 1880 annual report noted that “patients between the ages of 2 and 14, suffering from acute diseases, medical or surgical, are received at the Hospital. No patient is admitted whose case is considered chronic or incurable, unless in the opinion of the staff relief can be given . . .” In addition, patients known to be suffering from infectious diseases were not admitted for fear of epidemics sweeping through the entire patient population.

There were good reasons for these restrictions. Infants under the age of two could not survive institutional care; this restriction was common even in so-called children’s hospitals. It was not realistic for the hospital’s managers to admit patients with known incurable or contagious diseases; their concern was to make the best possible use of their limited resources. Thus patients admitted and treated successfully at Children’s Hospital tended to suffer from conditions most responsive to simple medical procedures and nursing care.

Despite the managers’ efforts, children inciting infectious diseases were often admitted; this put the entire hospital at risk from cross-infection. Within a few years of the hospital’s founding, the managers had to seek additional funds for a separate contagious disease or isolation ward. Some implications of the germ theory, developed by Koch and Pasteur, began to be understood in the 1880’s.

The managers and doctors at St. Louis Children’s Hospital were aware of the high child morbidity and mortality during the warm summer months. The most frequent source of fatal disease in the summer was contaminated milk. So many children died from gastrointestinal infections that the disorder was called “summer complaint.”

In 1884 the demand for more patient beds became so acute that the managers purchased a.
The first medical staff of Children’s Hospital, photographed in 1879. They were homeopathic physicians, and served as the hospital staff until 1910, when the St. Louis Homeopathic College closed.

lot on the corner of Jefferson and Adams Street; there they constructed a new building, “with accommodations for at least 60 patients . . . a ward for infectious disease, and an apartment designed as a dispensary for the poor.”

The dispensary, or outpatient department, was an important innovation. It served as both a means of screening and of prevention; serious cases demanding immediate care could be admitted, less serious ailments could be treated at home. The 1886 annual report noted, “the poor will often bring their children to the dispensary for treatment, when they will not leave them for regular treatment in the hospital.”

Parents’ reluctance to leave their children at the hospital may have been, in part, because of the extremely limited visiting hours: families were permitted to visit only one hour a week. This restriction reflected a fear of contagion as well as the lack of extra space within the hospital for visitors.

In 1888 the hospital’s annual report stated, “While our work is to relieve the ailed bodies, we also wish to make happier and better the lives and the hearts of those brought under our influence . . . .” An educational committee was formed to run an informal hospital school; in 1894 the managers reported, “Our primary school or kindergarten . . . has been a great blessing to the little sufferers; it has kept their minds employed . . . .” That year, Mrs. Laura Weil agreed to provide an endowment to support a teacher’s salary.

The hospital’s financial position was further strengthened in 1894 by the addition of Robert S. Brookings to its advisory board. Brookings’ dual interests in Children’s Hospital and the Washington University School of Medicine had a profound effect on both institutions in the 20th century. By 1900 the impact science was visible at St. Louis Children’s Hospital; isolation and antiseptic techniques were in use. In 1903 the Managers purchased “a microscope, an x-ray apparatus, a vibratory appliance, a new sterilizer, hot and cold distillers, and a pathology table, the best in the city.”

The admission policy changed to allow infants and children with contagious diseases to become patients. This change reflected the increasing confidence and effectiveness of medical care by the turn of the century. It also marked an important transition in the public perception of the hospital — from a place of last resort for the poor to one
where everyone in need of medical care would come for treatment. Johns Hopkins had set the pattern of the teaching hospital in 1894; there a hospital was planned as an integral part of the new medical school to provide patient care, teaching, and research on one site.

Before this time, patient care and medical education tended to be separate enterprises, although doctors might make visits with their students to certain hospitals. This was the practice at St. Louis Children's Hospital from 1886 onwards; students were brought in "for instructions, and practical lessons in medicine and surgery." However, the medical staff continued to be an attending one, supplemented in 1885 by the first so-called "resident" physician. The idea of a full-time medical staff and a full-time medical school faculty were both 20th century developments.

The foundation for the affiliation of Washington University School of Medicine with St. Louis Children's Hospital, and the idea of a full-time medical staff and faculty, came about as a result of Abraham Flexner's famous 1910 report on American Medical education. Robert Brookings, who was on the board of both the Hospital and the University, asked Flexner to make a special visit to St. Louis to share his recommendations with him. On his first visit, Flexner had been critical of the facilities at Washington University Medical School. Once he was sure that Brookings and his fellow board members were serious about improving standards he wrote favorably in his report of their efforts.

Washington University, St. Louis, is marked out as the natural patron of education in Missouri. Its importance is bound to be more than local... There is abundant evidence to indicate that those interested in Washington University appreciate its 'manifest destiny'; it bids fair shortly to possess faculty, laboratories, and hospitals conforming in every respect to ideal standards...

The women managers of Children's Hospital, and particularly Mrs. Grace Jones, were well aware of trends in medical education and their possible effect on their institution. At just the time Flexner and Brookings were planning the reorganization of WUMS, the homeopathic medical school in St. Louis closed. As Mrs. Jones herself recalled, "It was a most opportune time for the Children's Hospital (to affiliate) because it would thus be put on a modern scientific basis."

As old friends, Mrs. Jones and Robert Brookings agreed to the affiliation of the hospital and the medical school over tea; this informal 1912 agreement was followed by two legal contracts, specifying the relationship between the two institutions and finalizing plans for Children's to move to a new site, next to the Medical School, on Kingshighway.

That same year, the Children's Hospital opened a "country department" for convalescent and tuberculous patients called Ridge Farm. During this interim period, from 1912 to 1915, both the city hospital and the country department were run by the Board of Managers with a committee of the WUMS faculty.

This proved to be an awkward interval, particularly for the first chairman of the new department of pediatrics at the Medical School, John Howland, M.D.* After only six months here, Howland resigned in 1912 and later took the chair of pediatrics at Johns Hopkins. A major cause of his dissatisfaction was the location and poor condition of the "old" Children's Hospital, still on the corner of Jefferson and Adams.

Nonetheless, in the years after 1910, the hospital continued to expand its activities in the old building. The Martha Parsons Free Hospital, which had specialized in orthopedic care, became part of Children's Hospital in 1910. That year medical social service was established through a special grant from the Board of Managers. This innovation was popular with doctors and patients.

*John Howland, M.D., was chosen as the first chairman of pediatrics at Washington University School of Medicine in 1910. His expertise was in pediatric biochemistry, of particular concern at the time. His successors as chairman, W. McKim Marriott, M.D., (1916-36) and Alexis Hartmann, M.D., (1937-64) were also experts in this field. The present chairman of pediatrics, Philip R. Dodge, M.D., is a specialist in neurology.
it was seen as a means of insuring the health of patients discharged from the hospital. As the annual report for 1910 stated:

"It is useless to spend all the energy and money on curing a child and then to return it to the same conditions that produced the disease."

Social workers sought help for needy families and instructed parents on proper nutrition and child care; they also helped obtain needed appliances such as braces and glasses.

Medical social work was part of the general interest in preventing childhood disease; this became a major goal of Children's Hospital in the 20th century. To insure a supply of safe milk for infants, a clean milk station was established within the hospital in 1904; by 1910 more than 25,000 bottles of pasteurized milk were distributed annually. In addition, feeding and well-baby clinics were run by the hospital to make sure children were receiving proper nourishment.

Pediatricians' concern with infant nutrition in the early 20th century was a result of the high infant mortality rate from intestinal infections or malnutrition. Much research in pediatric biochemistry and bacteriology was directed toward finding a safe and satisfactory infant formula. The second chairman of pediatrics at Washington University School of Medicine, W. McKim Marriot, M.D., was noted for his research in this field. His appointment came in 1916, after a national search; he was given the dual titles of chairman of the department and pediatrician-in-chief at St. Louis Children's Hospital.

By that time, the affiliation between SLCH and WUMS had been put on a firm basis. In 1914 Robert Brookings had made a successful application to the General Education Board for funds to create full-time departments of medicine, surgery and pediatrics. In his application, Brookings stressed the integration of the medical school and the associated hospitals:

"In addition to the powerful community of interests which these relations create, the plant is physically so unified that it would be practically impossible ever to separate it into its component parts . . ."

When the newly-reorganized medical school and the associated hospitals opened near Forest Park in April of 1915, there was a three-day celebration attended by local dignitaries and out-of-town notables from both American and European medical schools. In the major addresses for the occasion, the theme of the hospital's new relation to the university was stressed. Borden Veeder, M.D., of the Children's Hospital medical staff said, "The day has passed in which a hospital restricted to the care of the sick alone justified its cost and existence, and today if we were to limit ourselves to this purpose we would be far from fulfilling our debt to the community . . . the university connection implies the development of the scientific and research side of the hospital's work . . . and opens a field by which the hospital may extend its work far beyond the mere treatment of the individual child . . .".

Little was said at these ceremonies about the role SLCH had played in the hospital's development. However, a poignant reminder of their work appeared in the 1915 annual report, written by Minnie Bulkley, herself a former manager:

"It seems as if ages of time and a continent of effort must separate the splendid new Children's Hospital, so efficient and so immaculate, from the old house . . . where the work began. There were gathered 15 or 20 children under the care of a quite untrained but motherly matron. Each child was personally known to the board . . . I have no doubt the children are a 1000 times better off now than they were in the early days, but I am grateful for the fact that I was a manager in the very early times. It might have been hard on the kiddies, but it was very good for the managers . . ."

This ingenuous statement says much about women's work in the early development of Children's Hospital. They were amateurs in health care, motivated by humanitarian concern and a need to use their energies for the public good.

In later years, both Robert Brookings and Marriot acknowledged the crucial role women played in the development of Children's Hospital. In 1921 Brookings wrote to Abraham Flexner, "Mrs. Robert McKittrick Jones is really the St. Louis Children's Hospital. She has not only personally raised the funds for the erection of the buildings but has secured a large list of annual subscriptions and an endowment fund which approximates one million dollars . . ."

On Mrs. Jones' retirement as president of the Board of Managers in 1925, Marriot said: "During the period of Mrs. Jones' administration, she and her splendid board have brought Children's Hospital 'out of Egypt' and into the 'promised land.' During the building of the hospital Mrs. Jones was on the grounds almost daily. She . . . added many improvements which before that time had not been present in children's hospitals . . . Mrs. Jones and the Board of Managers have always taken personal interest in every part of the work of the hospital . . . Mrs. Jones was instrumental in affiliating the hospital with the medical department of WU, and this affiliation has been a most happy one . . . Such achievements by women of ability are the striking characteristic of our age . . ."

Mrs. Jones and her Board of Managers survived the awkward transition of SLCH from a small institution to a component of a major medical center. She and her successors continued to work enthusiastically for Children's Hospital for many years after 1915. Mrs. Jones' predecessors, Mrs. Appoline Blair (1879-83) and Mrs. Hugh McKittrick (1883-1907) saw their dream grow from a small rented house to an established institution.

Mrs. Jones' successors, Mrs. George Markham (1925) and Mrs. Harry Langenberg (1945-50), dealt with the increasing complexity of Children's Hospital as presidents of the Board of Managers. In 1950 the hospital's by-laws were changed, and the Board of Managers was replaced with a Board of Trustees.

The last woman president of the Board of Managers, Mrs. Harry Langenberg, died in May of this year at the age of 101. She began to work for Children's Hospital in 1908. Her interest in Children's Hospital spanned nearly three fourths of a century, and her life encompassed its transition from a rented house to a ten-story tower. The five women presidents of the St. Louis Children's Hospital Board of Managers shared with other men and women of their generation a belief in the special value of children. This had a profound effect on the growth of pediatrics in St. Louis and at WUMS. With the help of their friends and the St. Louis community, they have built a foundation strong enough to sustain Children's Hospital in its second century.
A Quiet Revolution in Childhood Cancer

By Sharon Stephens
Today, the enemy — childhood cancer — is the same, but the battle and outcome are quite different. Recent advances in children’s oncology have been so pronounced that even conservative medical authorities call them spectacular.

Washington University scientists and physicians at St. Louis Children’s Hospital are on the front lines of medical research and have played a significant role in the development of new treatments for childhood cancers.

These new treatments bring many children into remission — cancer free periods of normal life, with school and play and dating. The remissions of many children with particular forms of cancer have lasted so long that doctors think their malignancies may never reappear.

For instance, children with acute lymphocytic leukemia (ALL), the most common childhood cancer, have a 50 percent chance of being able to hold a remission for five years. Of those who reach the five-year mark, about 85 percent are expected to live a normal lifespan. Twenty years ago almost every child with ALL died within a few months.

The next most common forms of cancer in children are brain tumors; tumors of the lymph tissues, such as Hodgkin’s disease and non-Hodgkin’s lymphoma; Wilms tumor, of the kidney; neuroblastoma, a malignancy of the sympathetic nervous system, rhabdomyosarcoma, a muscle malignancy; and osteogenic sarcoma, a bone cancer.

The survival figures depending upon the specific situation and form of the disease range from 80 percent for Hodgkin’s disease and Wilms tumor to 60 percent for bone cancer and 20 percent for brain tumors.

Fortunately, childhood cancers are rare,” says Teresa J. Vietti, M.D., professor of pediatrics and head of the Division of Pediatric Hematology and Oncology. “The most common form, ALL, has an incidence of one per 3,000 per year, with a total of 7,000 new cases of childhood cancers being diagnosed each year.”

Even though rare, cancer claims more lives of children under 15 than any other disease, accounting for one out of 28 deaths, topped only by accidental deaths. Adult cancer is much more prevalent, contributing to one out of six deaths. For every 50 adults stricken with cancer there is only one child diagnosed with the disease.

It is thought that childhood cancer is contracted for reasons different from the causes of adult cancers. Because environmental carcinogens take some 10 to 20 years to erupt into malignancy, researchers think that genetic factors may be behind some childhood cancers. There are a few carcinogens, however, that appear to be able to cross the placenta from mother to fetus.

“The types of cancer that children contract are also different from those adults contract,” says Vietti. “Adults most frequently develop carcinomas — the malignant growth of tissues that line the inside and outside of the body — such as lung cancer and stomach cancer. Children usually get sarcomas which arise from the mesoderm and thus affect connective tissue, muscles, kidneys, bladder, etc.”

Childhood cancers are also different in that they grow very rapidly, metastasize very early and will kill the child quickly if nothing is done. Adult tumors, on the other hand, grow very slowly, metastasize late and are relatively insensitive to drugs, whereas children are very sensitive to the drugs.

While children in general do respond well to drugs, very young children, those less than a year old, tolerate therapy poorly. A child can be born with leukemia or cancer. The most common type of cancer at birth is neuroblastoma.

“Neuroblastoma is a disease of the sympathetic nervous system,” Vietti explains. “Actually, it is the only disease where we haven’t really made inroads.

“Survival, despite what we do and regardless of the patient is about 30 or 40 percent. We’ve probably prolonged their life with chemotherapy, but we haven’t been able to cure them of the disease.”

Much more success has been realized with acute lymphocytic leukemia. Researchers are currently dividing the disease into subsets in an attempt to isolate the factors that determine whether a child will live or not.

“We have identified three subsets,” Vietti says, “the T-cell, B-cell and L-cell. Children with L-cell disease do the best and fortunately that’s the greatest majority of children. T-cell accounts for about 15 or 20 percent of the children and B-cell disease accounts for two percent.

“We’ve just started looking at these so-called subsets of diseases so we don’t know yet how much information the study is going to yield.”

Because cancer is rare in children, especially some forms of cancer, researchers at any one institution may not see enough of the disease. To combine their efforts with other researchers, cancer scientists at the School of Medicine are members of the Southwest Oncology Group, a research cooperative with members throughout the country. Vietti is vice chairman of the Group and head of the pediatric division.

There are only between 30 and 40 new cases of acute leukemia diagnosed a year. Any one institution simply does not see enough cases to formulate and achieve meaningful research goals.

For scientists in the Southwest Oncology group chemotherapy is the major avenue of research. Of particular interest is how surgery and radiation therapy fit in with chemotherapy.

“Now that we can effectively treat a lot of cases with chemotherapy,” Vietti says, “do we have to have mutilating radiation therapy as in the past? Or can we cut down the amount of radiation therapy and still get the same result?”

“We are also looking for new drugs,” Vietti says, “which are more or just as effective, but less toxic than the ones we are using.

“We are also investigating whether there are children that just don’t require as much therapy as other children. How can we reduce this therapy and still get the same result?”

A multidisciplinary approach is taken in this research, as well as in treatment. Chemotherapists, radiation therapists, pathologists and surgeons work together to establish the best possible regimen for each individual case.

Investigators have been working together to determine whether patients with Wilms tumor, rhabdomyosarcoma and bone cancer need to have radiation therapy when their tumor has been totally...
excised surgically. "We're finding out," Vietti says, "that we don't have
to give radiation therapy.

"The problem is that about two to three percent of the patients
who get radiation therapy eventually develop a second tumor," she
says. "The tumor may be benign or malignant. We do sometimes have
a patient whom we've cured of the disease, but develops a second
cancer and dies.

Vietti also feels that drugs in some cases may cause a recurrence
of cancer. "The drugs we use are very powerful," she says.
"We're trying to kill abnormal cells in the body and there is no
reason to think we're not going to be damaging some of the normal
cells. We see many of these cancers developing 15 or 20 years later
and we really haven't followed enough of the children to know what is
causing these recurrences."

Scientists are also looking at what causes cancer in children in
the first place. "We really don't know," Vietti says. "There are some
diseases, hereditary diseases which make people, adults and children,
prone to develop cancer, but these are relatively rare.

"Strangely enough, children who usually develop acute leukemia
are children who live in suburbs, are from a large family and are
usually the healthiest child in that family.

"A child in the slums is less likely to get leukemia," Vietti says.
"Maybe he has developed some resistance to the disease or his whole
immune competence may be higher. I don't know."

Because children who contract cancer are usually healthy,
immunotherapy, a relatively new approach where the victim's immune
system is enhanced to fight the cancer, has been unsuccessful.

"Immunotherapy was very attractive for a while," Vietti says. "But
most of the trials have been disappointing and as someone stated; we
have to go back into the lab and see why we can get such good results
in the experimental animal and yet we don't seem to translate this
to human treatments."

Vietti and her colleagues are investigating a therapy which
attempts to mature the cancer cells and get them to behave like normal
cells. "Unfortunately this hasn't worked," she says. "Eventually, I think
this is the way we are going to go but we will have to know more about
the basic biochemistry of the cell. When we get to the point where we
can alter the cell and differentiate it into a normal and mature cell —
the patient is probably cured."

Bone marrow transplants, also relatively new, have shown more
success than immunotherapy, particularly with patients with
acute myelogenous leukemia where there is little chance of
curing it by other means.

Because of the wide variety of possible treatments for different
cancers, children with cancer should be brought to a large medical
center to insure the best possible care, Vietti says.

"Even if we train someone in the treatment of children with cancer,
the treatment mechanisms change within four or five years," she says.
"Secondly, well-trained personnel are needed for outpatient care. Not
just pediatricians, but radiation therapists, surgeons, pathologists and
social workers who are used to taking care of these types of children.

"You have to have a multidisciplinary team," Vietti says. "If the
child develops a complication and needs to be admitted it usually
requires very intensive therapy with a well-trained house staff. You
need the backup support personnel of infectious diseases, cardiology, metabolism, neurology and neurosurgery.

"Cancer in children is so rare outside a medical center that a pediatrician who takes care of 2,000 children will only see one or two children with cancer in five years," Vietti says. "So he just doesn't have the experience that he needs to take care of these types of children.

St. Louis Children's Hospital/Washington University Medical Center sees children with cancer from a 200 mile radius. Many of these patients come to Children's not yet knowing that the diagnosis is cancer.

Perhaps the child has an infection that doesn't respond to antibiotics, or they have bone or joint pain or a mass has been noted during a physical examination. There are no specific symptoms of childhood cancer that show up for each of the diseases.

"One of the hardest things I have to do is tell the parent or the older child that the diagnosis is cancer. The absolute worst is when the child dies."

"Initially, you don't know the child or the parents, but after you have treated the child and worked with the parents for two or three years you become emotionally attached to the family. No physician likes to admit or accept failure."

Fortunately, the story of childhood cancer is no longer one of facing inevitable death, but rather one of struggling for life. The physicians and scientists who discover and administer new treatments are the real hope for the child with cancer. They are responsible for the cures. However, almost equally important are those professionals concerned with the care of the patient and his family.

At St. Louis Children's Hospital three women are very much involved with the children and their families: Karen Beckett, clinical oncology nurse; Anita Gill, pediatric nurse practitioner, and Jacque Schaefer, social worker.

"I'm often the first person to counsel the family," Beckett says. "I see the child and parents during or as soon after the diagnosis as possible. They are given a full diagnosis and prognosis and all the current information about the treatment, but they absorb very little. All they hear is that their child has cancer."

Panic, denial, shock, grief, victimization, rage and a feeling of total helplessness are emotions experienced by parents. Guilt is also a reaction: guilt about the anguish they feel, about possible genetic causes of the child's disease, guilt about being prevented from spending time with other members of the family.

"One of the first things to consider is what to tell the child," Beckett says. "There is still much disagreement between professionals and parents. Years ago a child was never told he had cancer. Some parents still do not want their child told, but we have come to realize that children are a lot smarter than we think and figure things out for themselves."

The trend in most medical circles is toward complete honesty. Doctors urge parents to tell the child as much of the diagnosis as he can understand. Health care professionals say that children inevitably sense their parents' distress, and that when they face hospital treatment they are bound to guess what is going on. Many children find out from playmates or overhear conversations between their neighbors about their illness.

Karen Beckett (left), clinical oncology nurse, and Anita Gill, pediatric nurse practitioner, administering chemotherapy to Jeff Shannon.

Researchers feel that the loneliest of children are those who are aware of their diagnosis but at the same time recognize that their parents do not wish them to know.

Tests show that those children who are fully aware of their diagnosis and can openly approach their parents for reassurance cope with treatment better. They also tend to cope with life better.

"We never lie to the child," says Jacque Schaefer. Those who are not told exactly what their disease is are given an accurate description of their disease and their treatment. We just leave the word cancer out.

"But over the years the doctors have felt that children should know about their disease, even those as young as three or four."

Ten years ago when a child was given a diagnosis of cancer he and his family prepared for death. Today, they must prepare for living, while enduring a constant shadow of uncertainty.

This uncertainty is not only whether they will live or die, but it pervades their whole existence. What will their friends say, how will teachers react, will a new treatment be successful, will it be more painful, what new side effects will appear, the list is endless. Then when they appear to be "cured" they worry if it's real, about the long-term effects of drugs and radiation and the chance they could pass a cancer to their offspring.

"Technology is moving fast," one oncologist says, "but psychological coping is not. The stress of living with cancer for years is more than some people can take. If there is one time when children need help, it's after they have lived a number of years."

At St. Louis Children's Hospital the help starts at diagnosis and is always available. "Initially I try to interpret the medical information and the treatment which has been recommended," Beckett says. "I act as a liaison between the parents and the physicians.

"We talk about finances as soon as possible and what resources are available in the community."

Often parents will say that money doesn't matter, just give their child the best possible care. But the blow to the family's finances can be as bad as the blow to their emotional stability. Shirley Lansky, M.D., of the Department of Pediatrics and Psychiatry at the University of Kansas Medical Center, has studied the problem thoroughly and has come up with shocking conclusions. Any disease that costs the family more than 15 percent of their yearly gross income is normally considered catastrophic. Lansky discovered that nonmedical costs alone for having a child with cancer came to 25 percent. The bills are limitless: extra food for the patient, food eaten out, lodging for the parents, transportation to the medical center, babysitters, wigs, wardrobes for weight loss and gain. These debts, in addition to medical costs that are not covered by insurance, can leave parents facing bankruptcy.

While most patients have private insurance it is usually inadequate for the long-term outpatient care required. "We like to reassure them that there are resources to help pay for care," Beckett says. "We don't want the family to be hopelessly in debt before they realize it. The money is important for the child, but it is important for the family too, since they have to live as well."

Finances are one source of worry for parents, but another is their feeling of helplessness. "Parents want to help their child get well, but all they can do is stand by and watch their child getting painful treatments," says pediatric nurse practitioner Anita Gill. Gill gives physical exams and administers chemotherapy to the children who are out-
patients. She provides the continuity of care that is sometimes non-existent in a teaching hospital where house staff may change three or four times during the course of a child's disease.

"It helps the parents when I tell them that we realize how painful it is for them (parents). I've been a patient and a parent myself and I assure you it is much easier to be the patient than the parent.

"Parents feel so helpless. A lot of what I do is supportive care; just reassuring the parents and telling them the value of what is being done so they know it's the right thing."

Many parents have found a constructive remedy to their feelings of helplessness in the Children's United Research Effort (CURE).

With the inspiration of Jacque Schaefer, CURE was founded in 1967 by parents whose children had cancer or leukemia. Meeting to discuss common problems, they soon became aware of the urgent financial needs of the hospital's research program.

The group is continuously raising money for cancer research. But parents involved also provide a needed support system for each other as well, emotionally and sometimes financially.

Susan Hollenback, current president of CURE, became involved with the group when her daughter was diagnosed as having leukemia. "Since I couldn't cure leukemia," she says, "I wanted to do something to help those who could.

"It's a very frustrating feeling. You have to fight the disease the only way you can."

The Hollenbacks lost their daughter in 1972 and have since been very active in CURE. "Most of the board members have lost children," she says. "When you have a child in treatment you don't have much time for anything else."

One of the group's projects is to establish a resident house for parents who travel from out-of-town to Children's Hospital. They also sponsor bimonthly speakers on relevant topics and in-clinic parent discussions every Tuesday. These discussions cover every aspect of the parents' problems from behavior to side effects of drugs to knowing whether a child should go to school on a given day.

"Knowing when to send the child to school and when to keep them home can be a problem," says Jacque Schaefer. "If there is no disease like chicken pox, measles or flu going around at school then it is usually okay for the child to go.

Chemotherapy lowers the child's resistance to infections, so they not only get more colds than a normal child but they are more susceptible to other diseases.

"The child is usually aware of when he is feeling too bad for school or other activities," Schaefer says. "But there is always the question in the back of the parent's mind 'am I doing the right thing.'"

However, parents' and children's determination to live as normally as possible usually keeps them involved in school and other activities. One reason is that the child who is cured of cancer won't be wholly cured if he can't function on his own in society, if his mental and emotional development is at a standstill.

"If a two-year-old child is treated as a two-year-old until he's six, he is not going to make as good an adjustment as child who is allowed to develop normally from a psychological standpoint," Schaefer says. Another reason is that if a child is consistently treated as if he is sick he will surmise that he must be dying and nothing really matters anymore.
Important as school and a normal life may be, achieving it may be difficult. "As strange as it may seem," says Schaefer, "some people still think cancer is a contagious disease. There's also the fear that a child with cancer will suddenly die.

"Many times we call the child's school and talk with them about the child and the disease. We emphasize that the child is trying to live normally and should not be given special treatment."

Discipline is just as important with a child when he has cancer as when he doesn't. However heartless it may seem to scold such a child, it is worse to make it appear to him — as it will if he is overindulged — that his parents have given up on him.

It's very important that children believe they are going to get well. Researchers say that if you treat a child as if he is going to die then it is much harder for him to achieve a cure.

Achieving that cure, however, can create additional problems with the child's self-image. Chemotherapy drugs can cause a number of side effects. The worst from the child's point of view are those causing loss of hair and obesity. Wigs and the assurance that when they can quit taking the drugs their hair will return and the weight can be lost are the only answers.

"Why did this happen to me?" is a question that also plagues the child's self-image. Afflicted children, especially younger ones, wonder if they are really worthwhile or whether they did something wrong to deserve this disease.

"There are problems on many different levels," says Karen Beckett, "for these children and their families. I believe in a holistic approach to health in which we treat the physical, mental and emotional manifestations of the disease, and this has to take into account the whole family."

Treating the whole family often includes siblings. Brothers and sisters of a child with cancer have little time with their parents. They are usually left out. They feel guilty about their understandable jealousy of the attention the sick child gets, and they often also have guilt feelings that something they said or did caused the illness.

"Siblings are one of my worries," says Jacqueline Schaefer. "I usually try to get the parents to look at the needs of their other children and give them equal time and consideration because their future is important too. If parents consistently allow the child with cancer to come first, they could lose the other child."

But for the most part the affliction usually brings a family closer together. "It is really adversity that makes you strong," says Anita Gill. "I have seen it happen."

It's important for the family to communicate to achieve this bond. "One of the biggest problems that children have is reacting to their parents' acceptance of their disease," Schaefer says. "I think that if the parents can learn to accept it they can foster the needed communication."

A child may feel it's necessary to talk about their death. After internalizing a lot of information they pick up from their parents, doctors and other children, a child realizes that there is a possibility that he may die. If they can talk about it openly in the family it helps.

Karen Beckett tells a story of a boy who overheard doctors talking that he wouldn't make it. "Gary told me one day that he knew he was going to kick the bucket," Beckett says. "I asked him how he felt about it and he said, 'It's okay, because if it's time for me to go, I'm ready.'"

"When I first met Gary, he was a rather unlikeable kid," Beckett says. "But as time went on he really matured and grew up emotionally. He developed a strong character and became good friends with his classmates. Gary always brought a big wooden cross to the hospital with him. The last time he came to the hospital he forgot the cross, but showed it to a friend who said 'I carry this to remind me I must pick up my cross and bear it daily.'"

"A few days later the nurses called me and said Gary was dying. I went up to his room and held him. He looked up at me and said, 'Karen I love you,' and then he died. A few days later at his funeral I found out he had told his pastor that he had known he would die. The pastor said Gary was ready to die but said he wanted all his friends to be in heaven with him."

Karen Beckett doesn't tell his story without emotion. She and the other professionals who deal with these children and their parents don't do their work without emotion either. What they have to do and what they see is sometimes painful, but it's also hopeful and even joyful at times.

"Years ago if a child had leukemia you gave him a month or two; today we have our own success stories," says Anita Gill. "To see a mother coming back with her own baby, after having cancer as a child and surviving, is a real thrill for all of us. Even if you can't cure someone, just to help them and give them some valuable time is very rewarding."

"People think that our clinics are depressing places," Gill says. "But they are not. The parents and children come in and they are cheerful and in a good humor. If you have a small problem that you've been worrying over yourself, suddenly your problem becomes very minute. Around here there is a lesson in heroics everyday."

Karen Beckett gets to know the patients on their level.
After 20 Months, Teddy Goes Home

By Marla Finer

The fourth floor of St. Louis Children's Hospital boasts something no other floor can match: a photograph of Teddy Moore hangs over the nurse's station. The blonde two-year-old's smile serves a dual role in that position. Not only is it a welcome to newcomers, but it is also a reminder to everyone in the hospital of a very special case.

Teddy was admitted to Children's Hospital in late September of 1977. His parents, Mr. and Mrs. Ted Moore of Wheaton, Mo., realized something was wrong with their child but no doctor could identify the problem. Finally, a Springfield neurologist who had done his pediatric neurology training at Children's Hospital referred Teddy here.

Carolyn Corbett, the patient care manager on the neurology floor, fondly remembers the little boy and the long treatment he underwent. "Teddy came here when he was eight months old with a diagnosis of failure to thrive. This is a general diagnosis used for children that aren't growing, gaining weight or developing normally. When Teddy came to Children's, he was so weak he could barely lift his head off the bed."

Teddy's general weakened state was diagnosed as mainly the result of a neuromuscular disease, Corbett says. "He had to expend all of his energy just on breathing and staying alive. When I first saw him he looked almost blue."

Doctors concluded that Teddy had an unknown neuromuscular disorder. He also had a problem diagnosed as laryngotracheal malacia, or an incompetent trachea and larynx. They were forced to perform a tracheotomy and after the operation Teddy required mechanical ventilation. He was placed in the intensive care unit in October and

Mary Ann Dittmaier, R.N., (left) and Carolyn Corbett with Teddy at the fourth floor nurse's station.
remained in the ICU on a respirator until the following June. During this nine month period, Teddy had several serious bouts with pneumonia and each recovery was painfully slow.

Although Teddy was gaining some weight, he was still underweight and undersized for his age. More seriously, Teddy was having difficulties moving his diaphragm by himself. At best, Corbett remembers his efforts were minimally effective in coughing up phlegm, which was necessary to minimize the risks of pneumonia.

The doctors suspected his diaphragm might be paralyzed. Phrenic nerve stimulation and medicine with electro-medical maintenance both failed to help. The physical therapy department even made a rocking bed for him similar to those used by polio victims for respiratory stimulation, but that too failed.

Teddy was quickly becoming a favorite because of his friendly personality. The hospital staff was totally charmed by him. He constantly had visitors and attention, but his condition did not improve. That's when Corbett and others decided to try and change Teddy's chances.

"He wasn't off the respirator at all and he had a lot of behavioral problems, some probably just from being in the ICU," Corbett remembers. "The doctors thought it might have been partly a behavioral problem and not a physical one, so we decided to take a risk. We put Teddy on a strict schedule." And night situation. This involved some behavioral modification for both Teddy and the hospital staff. Teddy had a primary nurse, Tia Choy, and a primary respiratory therapist, Elaine Bollis, who worked closely with Corbett and Staenberg in planning and carrying out his care.

Shortly after Teddy's removal from the ICU, Corbett and Staenberg began weaning him from the respirator by taking him off it at different times of the day. Teddy still needed help breathing during these times and the respiratory therapists became increasingly important for his improvement.

Teddy soon began eating in a high chair and joined other children on the floor when he ate his breakfast. This was just one of the many steps Teddy took in his program of catching up. Corbett and Staenberg's goals included teaching him how to eat solid foods, to feed himself, to crawl and walk, to speak and most importantly, to get him off the respirator and breathing by himself.

"It was a very strong bond between the family. "Teddy always knew who his parents were; there was never any question that they were his favorites," she says. "Of course," she continues, "during the time he was here, he became very attached to several people, and we also became attached to him. But he never would choose us over his parents when they came." "I wonder how he could be normal. When taken off the respirator, Teddy occasionally requires manual ventilation."

Teddy's parents continued working in Wheaton while their son was in the hospital and the 300 miles separating the family put some limitations on the number of visits. But Corbett sensed that there was a very strong bond between the family. "During the time he was here, he became very attached to several people, and we also became attached to him. But he never would choose us over his parents when they came."

Corbett glows when she remembers the little boy. "You wonder how he could be normal."
When you think of a new child spending the first two years of his life in an institution, you think he's really going to have some mental problems. But he did spend the first seven months of his life with his mother. It's just incredible how normal and social he is.

In October of 1978, Teddy was off the respirator for 12 hours at a time on good days, although he still needed to be manually bagged, and could stand by himself. His progress was encouraging and Corbett approached Darryl DeVivo, M.D., the neurologist following Teddy's case, and asked about sending the boy home.

DeVivo agreed and Christmas was the target date, but plans did not run smoothly. Several setbacks forced the postponement of Teddy's return until the spring. He had pneumonia in December and then two more times before he was finally released in April. Teddy's stay lasted a total of 20 months and cost more than $280,000, a bill Children's Hospital paid in full.

Corbett was just as instrumental in planning Teddy's return as she had been in helping with his recovery. October was the first time Teddy's parents and medical staff met to discuss bringing him home. "His parents were a little scared of all the things that would have to be done," Corbett remembers.

"We made a list of all the equipment that would need to be purchased or rented, what sort of people would need to get involved and what kind of arrangements we'd need to make, and then we started our planning." The planning involved Corbett, a physician, occupational therapist, social worker and respiratory therapist. Together they decided what needed to be done and then began contacting the necessary people.
DeVivo wrote to the Muscular Dystrophy Association and they agreed to pay for all the respiratory equipment Teddy would use at home. This included not only the respirator, but also the oxygen and suction catheters.

The family, however, was responsible for finding a backup generator in case of a power failure. The Moores are isolated from medical help in an emergency because the nearest hospital is more than 15 miles away and Springfield is 65 miles from Wheaton. The Moores again found aid, this time from the Mount Vernon Civil Defense who supplied them with a generator.

This isolation forces Teddy's parents into a unique position. For them to be responsible for their son, they must also be responsible for all his needs. While visiting Teddy, both parents learned how to administer Teddy's postural drainage, percussion and respiratory therapy. They learned how to change his trach and suction him, and became fully competent with the respirator. Corbett believes Teddy's parents worked hard to understand their son's equipment and it has paid off. "Mr. Moore can control the respirator and do everything needed. He knows more about it now than I do," she says.

These processes not only take a great deal of time to learn, but also take a great deal of time to perform. Corbett says, "Teddy needs respiratory therapy, postural drainage and percussion at least three times a day. These actions are necessary to help him bring up his secretions. They take half an hour to 45 minutes and also require suctioning. Teddy's respiratory status must also be continually evaluated. Each decision concerning his health must be carefully understood, but his parents were very motivated to learn."

There were other plans to be made before Teddy could go home. Mike Gruzelski, the department manager in respiratory care, coordinated several arrangements with companies all over the state for Teddy's supplies, while Corbett was responsible for finding a visiting nurse for Teddy. Both went to Springfield two weeks before Teddy's release to finalize plans with the staff at St. John's Hospital. Those who would be entrusted with Teddy's care received detailed discharge summaries from respiratory care, physical therapy, the nursing staff and the medical staff.

The day before Teddy's release, a respiratory therapist and his primary nurse drove to Wheaton with many of Teddy's supplies. They checked the respirator, set up the equipment and called Children's Hospital to inform them of the materials still missing. Then they settled back to await Teddy's arrival.

The following morning, Teddy left his friend on the fourth floor wearing an outfit a nurse had made just for the occasion. Corbett and Gruzeski rode with him first in the ambulance and then on the plane that took him to Wheaton. "Teddy was looking nervous" Corbett recalls, "but he was just real quiet. He didn't know where he was going and just accepted the situation because he was with a person he knew."

"When we got on the plane, he fell asleep in my lap and slept the whole trip. I woke him up right before we landed and he was looking out the window at the crowd at the airport. Then all of a sudden he saw his parents and he was so excited. He got off the plane and was just elated."

Gruzeski did not stay in Wheaton with Corbett and the others, but returned to St. Louis that day. He did see Teddy's parents though and remembers Mr. Moore's parting words to him, "If I never see you again, thank-you."

Corbett went home with the Moores, although it was not a homecoming in the normal sense of the word. "I don't think he knew what home was," Corbett explains. "He hadn't been there since he was an infant, but he knew who his parents were. Yet, he was acting like a typical two-year-old. He got into everything, he walked around and wanted to open things up and pour them out. He even tore up his mother's coasters, I think. It was just amazing. It was as if he knew he was home, even though he'd never been there."

Corbett, his primary nurse and the respiratory therapist remained in Wheaton for several days, helping the Moores settle into their new lifestyle. Teddy's room may still resemble a hospital, but he realizes he is no longer at Children's and seems ready to allow his parents the responsibility of his care.

Corbett remembers Teddy, "wanted his parents to do everything and he wouldn't let us do the things we normally did at the hospital."

Corbett has not visited Teddy yet, although she plans to go soon. She does speak with his mother twice each week by phone. Teddy shares the conversations but becomes confused by Corbett's voice without her presence. He kisses the phone anyway. Corbett learned that Teddy walks now and feeds himself. He plays in the backyard and has even been horseback riding with his father. Best of all, he is on the respirator less and less.

According to Gruzeski, Teddy will get a new respirator in July. He has outgrown his old one and because his dependence is reduced, he will need a less sophisticated model this time. This respirator, like the previous one, will be paid for by the Muscular Dystrophy Association.

Not only does Teddy's progress continue, but his family has adjusted well to having him home. After some searching, Teddy has a babysitter and his mother has returned to work. Corbett hears that the young girl and Teddy get along quite well; he tells her what to do and she does it. The girl is a recent high school graduate and believes she can take care of Teddy for as long as necessary.

Teddy will not return to Children's Hospital even in an emergency. "The distance involved is simply overwhelming," Gruzelski says. "Even moving Teddy's care to Springfield, 75 miles away is rather inconvenient. Teddy's progress will be followed by his pediatrician and a Springfield neurologist at St. John's Hospital."

There are still several answers researchers would like before they forget Teddy. No one knows exactly what happened to him, nor how to identify or prevent the same thing from occurring in another child. According to Corbett, "Teddy's illness was not discernable at birth. His mother said he ate a lot as an infant, but it seems that he just wasn't consuming enough calories to grow because he was working so hard just to stay alive."

Teddy's situation also leaves a clouded future. Corbett believes his maturation was not stunted by his illness, but it seems to have been slowed. "He has made so much progress during the past year that it seems he will just continue and catch up," she says. "If he continues to progress as he is now, by the time he's school age, the doctors believe he won't need a trach at all."

Teddy is not the first child in the United States that has gone...
home on a respirator, however, he is the first from Children's Hospital. Having him home is much more complicated than keeping him at the hospital. There are fewer people to care for him and more steps necessary for his care. But Corbett realizes this situation is the best.

"We felt there wasn't really anything more that we could do here for him," she says. "It wasn't the place for him to be and he was better off with his family. They do realize the risk involved with keeping him at home. But they believe even if he should become sick, which is possible, it was still worthwhile."

Health is still Teddy's major concern, but day-to-day living will strengthen him. As he gains weight and grows, his resistance will increase and there will become less likelihood of another serious case of pneumonia. His parents have been warned to take all necessary precautions and will bring him to the hospital at the first sign of illness.

Teddy's growth now depends upon the care he will receive from his parents and his local pediatrician. Corbett believes his chances are very good. "I think that his parents' ideas and values concerning Teddy's care are ideal. And he needs them far more than he needs us."

As much as Corbett and the Children's Hospital staff care for Teddy, they are happy to know he is home and doing well. They miss him, but Corbett sums up the feelings of everyone towards the little boy. "After seeing him home once, I would never want to see him in the hospital again. It was so nice."

Jim Hurster from respiratory care holds Teddy in one of the postural drainage positions.
Pediatric Rehabilitation: A New, Successful Service

By Patricia Corrigan Krauska

It began one cold January day in 1976 as a carefully planned experiment, initiated by two farsighted administrators. Two young women worked alone to establish and develop the department, under the watchful auspices of St. Louis Children's Hospital and Washington University's Irene Walter Johnson Institute of Rehabilitation (IWJ). Today, a dedicated staff of eight helps as many as 1,200 children each month through the St. Louis Children's Hospital pediatric rehabilitation service.

The service is the newest major department at Children's, but already its reputation for quality care and professionalism reflects a stature far in excess of its tender years. Credit for the idea to establish a separate pediatric rehabilitation service goes to Marvin Fishman, M.D., a pediatric neurologist and former director of IWJ, and Doris England, patient care director at St. Louis Children's Hospital. Phil Gustafson, an assistant director at Children's, is presently the administrator in charge of coordinating the service.

Mary Pat Hakan and Debbie Strobach, the two who worked many long nights to guarantee the growth of the department, now serve as senior occupational therapist and senior physical therapist, respectively. They share their duties with three other physical therapists, two occupational therapists and a much-appreciated secretary.

Strobach earned her Bachelor of Science in physical therapy at the University of Missouri at Columbia, worked at St. John's Mercy Medical Center in St. Louis for a year and a half, and then entered graduate school at the University of North Carolina at Chapel Hill, where she specialized in pediatric physical therapy. Hakan, who says she comes from a long line of "helper personalities," was attracted to the occupational therapy program curriculum in college because it combined psychology and science. She has specialized in pediatric therapy for about five years.

"These are the most enthusiastic people I have ever seen, and they have put together an excellent program," Gustafson says. "In the early days, they spent a lot of time educating physicians about the value of physical and occupational therapy. Then they built the service on the good experiences the (participating) physicians had there. They built it on the medical care model, and they are an integral part of what is available here."

Kind words from the boss are always welcome, but Hakan and the staff insist they flourish as a result of their environment. "We answer to both Children's and IWJ, and what is most exciting here is that the people are so dynamic. There is very little sitting around on the laurels," Hakan says. "Nobody is saying, 'It's new, so don't do it.' They
say 'Show us and we'll help evaluate it.' There is a lot of stimulation and challenge, and the emphasis is on creativity.'

With that philosophy in mind and their special skills in tow, the staff of the pediatric rehabilitation service offers physical and occupational therapy to children from infancy up to age 21. Clients, on both an inpatient and outpatient basis, are referred to the service by physicians at St. Louis Children’s Hospital. Patients' conditions are evaluated, parents are interviewed and a treatment program is established. After a certain term of therapy passes, another evaluation is held, and necessary referrals or follow-up take place.

Hakan explains: "We have two basic general services: rehabilitation and habilitation. We help restore functions which have been lost because of disease or trauma, and we help children who have not yet attained certain skills to learn them for the first time. We see ourselves as part of a team, working with the patients and their families.

"The emphasis of occupational and physical therapies is on health rather than disease," Hakan continues. "More and more people are being kept alive by scientific technology, but people deserve more than just existence. We come in and deal with the practicality of it all; we see what we've got, and we see what we can do with it. We can maximize the quality of life."

Physical and occupational therapies are complementary disciplines which do overlap in some areas. Some patients require both types of therapy; some benefit from just one. In general, problems requiring management which come under the direction of physical therapy include posture, balance, gait, strength, range, endurance, pain, muscle tone, sensation, circulation and communication.

Occupational therapy most often addresses itself to problems with behavior, problems with basic living skills such as feeding, dressing and hygiene, life skills such as those which affect home, play, work or school, cognitive skills, interaction with the environment, eye and hand coordination, gross and fine motor development and reflex development.

Within the two general fields, practitioners often specialize. Even within the specialization of pediatric therapy, further delineation is possible. For instance, Mary Pat Hakan and Debbie Strobach both especially enjoy working with newborns and very young children. Camilla Dude, a physical therapist with the department for over two years, has almost completed a graduate degree with pediatric orthopedic physical therapy as her major area of concentration. Sue Graber, another physical therapist on the service, is especially interested in seeing how she can help burn victims.

"But the most important thing," according to Strobach, "is the common goal of OT and PT: increasing the patients' ability to func-
tion to the best of their physical and mental capabilities." And more often than not, that goal is more easily attained with a little help from mom and dad. Parents of children with physical disabilities need information on how to help care for their offspring, and they need to know what to expect in the way of progress.

"When you're working with young children, there has to be a lot of family involvement," says Camilla Dude. "We can help parents in very practical ways by teaching them how to help the child with exercises, how to best hold the child; we can explain some basic do's and don'ts, and suggest several safety measures for them to take at home."

Also, after the immediate treatment program is over, the staff refers interested parents to community programs and agencies which might be helpful, recommends specific preschools, and offers advice for parents who have trouble carrying out a prescribed home exercise program. Though the service's primary approach is one of practical problem-solving for the disabled child and the parents, the staff has also taken note of the parents' emotional health.

Hakan explains it this way: "Many parents who come here express their anger and frustrations openly. Also, many parents of children with chronic problems often feel inadequate in the presence of professionals. We show them how to participate in their child's care, how to have some control again, how to influence the child in a positive way. We always educate parents about the sequence of learning skills, so they can be part of the evaluation process. Parents need to see progress, no matter how small."

Parents also want to know how to deal with their feelings. In response to that need, the pediatric rehabilitation service initiated a program called Hand in Hand for parents of children with developmental disabilities. The program is open to ten couples and is presented twice a year. The parents meet with various professionals one night a week for seven weeks, which includes three sessions with a developmental psychologist. The parents also look to each other for support and some of the "graduates" have continued to meet for educational and social purposes.

The staff is heartened by the response to Hand in Hand and also to what they believe is an evolving attitude of acceptance on the part of society toward handicapped people. Hakan reports evidence of the new attitude in educational mandates, "liberated" architectural requirements which provide for more ramps and fewer curbs and a new willingness to accept disabled people into the mainstream of life. "Suddenly there seems to be more social awareness; it doesn't seem to matter so much anymore if you happen to be in a wheelchair," she says.

And so the children come, in wheelchairs, braces and beds; they come to the spacious gymnasiums and treatment rooms, because their doctors have decided they can be helped. (And in the cases where patients at St. Louis Children's cannot come to IWJ, Haken, Strobach and the other staff members go to the children to assess, evaluate and plan treatment programs.)

Also, as in the early days of the service, the therapists go out and get patients who will benefit from treatment. But where once Hakan and Strobach concentrated on reaping the results of their intensive physician education efforts, now they have the opportunity to see many children face to face: they cover several clinics and are on call for still others.

"Our clinic coverage is vital to our program," Debbie Strobach stresses. "We screen every child who comes through birth defects clinic, we cover pediatric orthopedic surgery clinic, we go to premature clinic to do developmental evaluations, and we are on call for neurology and surgery clinics. Also, we try to see all burn patients at least once after they are discharged, just to see how they are doing with their exercise program."

Strobach elaborates: "I use the word 'handicapped' to describe a situation where a disability gets in the way of achieving something you can do, whereas if you have a disability, then that's a physical problem. When we first came here, there were a lot of handicapped children coming to the clinics; children with poorly-fitted braces, children who had no idea how to use crutches or get around in their wheelchairs. That has really changed. And as long as we are around, I can't imagine the situation reversing."

The department staff is still very much involved in physician education. "We make them aware of our service, of the kinds of things we can do," Strobach says. "Then we encourage them to be aware of their patients' progress, and potential." She and Mary Pat Hakan also provide in-service training for residents on a regular basis.

The physical therapy portion of the service offers a volunteer program for prospective and enrolled physical therapy students, and Strobach teaches in the physical therapy sequence at Washington University. She also speaks to high school groups about her profession, and along with Camilla Dude, has helped train city physical education instructors to screen for scoliosis.

"We would like to begin giving more workshops at Washington University as well as other places, because we really enjoy having our
department involved in the education of physical and occupational therapists," Strobach says. "And we want to start outpatient group programs for scoliosis patients, and maybe a few more support groups for parents, maybe one for parents of children with arthritis. We also worked with diabetic children for awhile, and we really want to get back to them too."

Camilla Dude admits the service is anxious to expand its services. "We've all worked hard to have staff positions added in the department, and we’re so glad to have the extra people to help," she says. "Still, even as we add more people, somehow we generate more work." Gustafson acknowledges too the service has a hard time just to keep up with the case load.

"They have made the time though, to participate actively in research," he says. "They are working hard, particularly in pediatric neurology. I think they have made some real breakthroughs in neonatology too, and I also know they are very busy educating parents. There aren't any numbers available on this, but we believe (the service's treatment) has shortened the length of stay for some patients."

The "no numbers" catch is of great importance to the service staff. "In the past, there was no documentation of the value of this type of treatment," Dude says. "Now we really see a need for research, a need to publish the results of what we have to offer. We are so close to so much knowledge . . . our natural response is to want to share that."

Debbie Strobach agrees that one of the primary goals for the service's future is good clinical research and an effort to publish the effects of particular treatment procedures on patient care. "But our first priority will always be to provide the best possible service to those children," she says.

Ironically, the care of "those children" comes from workers who have no children of their own. "Our jobs can be very draining emotionally and very frustrating," Dude explains. "And unfortunately, we sometimes have to do things that either hurt the children or that they just don't want to do. I think it would be very difficult to go home and be good to a family."

Mary Pat Hakan agrees; she admits she likes to go home in the evenings and know she doesn't have to smile as much there. "Part of the pressure comes too because we walk the tightrope all day between the positive and the realistic. We always emphasize what a child can do instead of what he or she can't do, but parents want to know the future. We just can’t promise them everything."

Still, occupational hazards aside, Hakan speaks for the staff when she says they all have very positive feelings about their work. "We enjoy the interaction, the chance to get to know people as we work with families. I would describe it as a mutually satisfying experience. I feel like I am offering something, but I think I benefit just as much as the patients do."
Reye Syndrome: Still a Mystery

By Glenda King Rosenthal

James P. Keating, M.D., professor of pediatrics and director of the Division of Gastroenterology at Children's Hospital, has had a long-standing clinical and research interest in Reye syndrome.
The doctors stands over the unconscious child and gravely tells the parents, "The next 48 hours are crucial." The scene is almost an anachronism, recalling scenes from medicine's past when the physician could do little but wait for a disease to follow its course.

F or a child suffering from Reye syndrome, time is of the essence; in a brief span of 48 hours the disease can result in death or total recovery. There are very few diseases in which we have a healthy child who, within a span of hours, is on a respirator suffering from a disease for which there is no antibiotic or specific medicine that can cure it," says James P. Keating, M.D., professor of pediatrics. "Some of the children who are stiff, unconscious and posturing are awake and eating breakfast two days later. They make a total and absolute recovery."

I mproving the recovery rate from Reye syndrome has occupied much of Keating's time during the past decade. Along with his colleagues at St. Louis Children's Hospital, Keating has developed an approach to the care of Reye syndrome victims which results in approximately an 85 percent survival rate. This lower death rate at Children's Hospital is in contrast to a nationwide mortality rate of close to 50 percent. In earlier years, 80 percent of the victims of Reye died within 48 hours.

"We've made many strides in improving the survival rate since the disease was officially recognized in 1963," Keating says. Even though symptoms of the disease can be traced in the literature back to at least 1923, the disease was not officially studied until 1963 with the publication of Dr. R.D.F. Reye's research. Reye, a pathologist, published a study of 23 children who suffered from an obscure form of coma and at autopsy were found to have extra fat in their livers. Reye then studied their medical records and discovered that all of the children had suffered from a sudden, intense illness which was usually diagnosed asencephalitis.

"Because of Reye's original research," Keating says, "we can now recognize a characteristic histological abnormality in the liver present with the syndrome. We found that liver tests done on patients in acute coma, even though they are not jaundiced and their livers are not enlarged, showed their liver enzymes to be very high. When this fact was discovered, the disease became known as Reye syndrome."

In the days before antibiotics were available, Keating said Reye syndrome would not have been as noticeable because there were many diseases that struck down healthy children. Today Reye syndrome is more readily identified because it usually occurs after the child has had a viral infection. The two most common infections that appear prior to the onset of Reye syndrome are influenza B and chicken pox.

"Since we have recognized Reye syndrome," Keating says, "we have never had an outbreak of influenza B in which an outbreak of Reye didn't follow. About one child in 20,000 who develops influenza B will also develop Reye syndrome. Epidemics of influenza B occur every three to four years, usually in January and February. Our worst year for Reye syndrome was in 1972; we had 17 children in our hospital in a single month."

Fortunately, most of the pediatricians in the St. Louis area are now aware of the syndrome and diagnose it early. However, the disease is still occasionally misdiagnosed as something else, usually encephalitis, drug ingestion or gastroenteritis.

Misdiagnosis occurred more frequently in the past," Keating says. "Now that the pediatricians in the area are well-schooled in the presenting manifestations of Reye, diagnosis is usually early and accurate."

An early and correct diagnosis of Reye syndrome is extremely important so that unnecessary and dangerous tests and treatments can be avoided. A correct diagnosis of Reye is now made fairly quickly by testing for liver abnormalities and checking for blood ammonia elevation. This early detection allows the physician to treat the more important symptoms of Reye, such as failure of liver, brain and respiratory function.

This rare syndrome follows a simple viral infection. The child often recovers from the minor symptoms of the viral infection, but begins to vomit persistently, he says. "He then becomes confused, agitated and combative. The child is frightened and doesn't respond to his parents. At this point, the child is usually brought to the hospital. The vomiting ceases, but the alteration in consciousness that begins as confusion ultimately progresses to coma. In a relatively short period of time, the child will either be dead or have recovered fully."

W ho are these one in 20,000 children, usually recuperating from influenza B, who will either die or recover from this swift, intense disease? According to Keating, who gets the disease and why is a perplexing area. "There are certain characteristics," he says. "It attacks rural children more frequently than it does suburban children, and suburban children more frequently than urban. Most of our patients come from St. Louis County; we have never had a case of Reye from St. Louis City in the past ten years. These observations are true of all major American cities. Why the suburban and rural child are at greater risk for contracting it is unknown.

Reye syndrome affects predominantly toddlers through teenagers. Occasionally, it is seen in a child under one year or in a person in his twenties. It also appears that once a child has had Reye, it is highly unlikely that he will get it again. Keating says there has only been one reported case in which a child had recurrent Reye.

The epidemiology of Reye is a fascinating, perplexing research area. "We've studied four families who have had two children struck by Reye syndrome," Keating says. "One family had one child affected in 1963 in Germany and the second child affected in 1978 in Cape Girardeau, Mo. These cases occurred 15 years apart in different parts of the world. Obviously, to understand the connection is a real challenge and a clue to methods of prevention."

A great deal of medical sleuthing goes on in an effort to understand the who and why of Reye syndrome. "We've done epidemiological studies, in cooperation with the USDA, in which we've gone out to the patient's home and taken a careful diet and events history," Keating says. "We took blood and urine samples from family members and even took samples of the meat in their freezers."

"This detective work is necessary. We don't have an animal model we can study in the laboratory, so we have to depend on clinical investigation and epidemiological studies for our knowledge of Reye syndrome."
Determined who will recover from Reye syndrome is somewhat more predictable than trying to determine who will come down with the disease and why. Keating says early treatment and diagnosis are an obvious advantage in improving the survival rate.

"The degree of coma the child presents with also makes a difference in his chances for survival," he says. "These patients can go deeper into coma than any other group of patients and still recover completely.

"We've measured innumerable things, such as hormone levels, degree of acidosis and liver and muscle function abnormalities, to try and gauge possible prognosis. There is really nothing definite that will accurately predict the eventual outcome of the disease, so we treat patients with all degrees of Reye quickly and intensely."

Reye is a disease that suddenly strikes down a healthy child, and the patient either dies or is recovering within two to three days. "Those of us working with this intense disease have two primary jobs," Keating says. "One job is to ensure that as many children recover as possible. Our other job, and a lot of our efforts and publications have been directed toward this goal, is to understand the disease once it is established so that we can modify the course of treatment."

The established course of treatment for the Reye syndrome patient provided at Children's Hospital is the result of trial and error and is now being used at most other medical centers. Keating attributes the high survival rate at Children's Hospital to "early recognition of the disease by area physicians, an established pattern of intensive support care along with excellent general pediatric intensive care."

"In the past we didn't support the patient who presented in stage 2 coma with a respirator," Keating says. "We learned that some children stop breathing, and by the time something could be done, some damage was done. So, we now intubate in stage 2 coma, start a central IV line to permit concentrated glucose infusion and place the child in an intensive care setting."

The Reye syndrome patient is constantly monitored and every four hours the adequacy of the patient's respiratory effort and the degree of cerebral swelling is measured. "We also do coagulation studies and check blood pressure and kidney output," Keating says. "We then modify our regimen, whether it's the respirator setting or fluid infusion, to try and minimize the impact of the organ failure that occurs for 24-36 hours."

This organ failure, particularly in the liver and brain, is what ultimately causes the damage to the patient. "All organ systems appear to be affected," Keating says. "Reye syndrome brings on a temporary, profound disturbance to organ function that doesn't necessarily result in damage to the cells. With this disease, the cells don't die but there is a profound failure of function. Our job is to make up for this failure until the disease reverses itself and, fortunately, this reversal often occurs quickly."

It is not known why this sudden reversal of the disease occurs, often without medical treatment in milder cases of Reye. "There are degrees of the illness, and this obviously will affect the eventual outcome, but at Children's we treat all degrees of Reye patients with intensive, supportive care," Keating says. "Another reason our patients might survive when others do not is because of what we don't do to them."

At other medical centers, Reye patients are treated in a variety of dramatic manners as a means of removing harmful toxins thought to be in the blood. "Many people in the scientific community believe there is some poison involved in Reye syndrome," Keating says, "but we really don't know if this is true. We certainly don't feel there is a good scientific rationale to do something extreme to remove the supposed toxin."

Three of the major ways of removing toxins are through dialysis, exchange transfusion and hypothermic wash-out. In this last procedure the patient is put to sleep and iced down. "All of the blood is then removed and replaced with iced salt water," Keating says. "The blood is then reinfused. To me, this procedure sounds like one step above the old practice of blood letting. However, there are places that not only still do this procedure but consider it a medical advance in the treatment of Reye."

These extreme measures in the treatment of Reye syndrome are not done at Children's Hospital. By providing the best supportive care possible, the Reye survival rate here is as good or better than at any other medical center.

Even with the current increased survival rate, Keating does foresee a time in the future when there is a more uniformly successful method of treating Reye syndrome. "Of course, presently there is a definite course of treatment we follow for each case," he says. "It is no longer a hit and miss affair. In the past we didn't even have a predictable course of treatment."

"I'd like to be able to say that we're doing something magically positive that contributes to our higher than average survival rate. In reality, we're offering what might be called consistent, intensive, supportive care. This requires a nursing and house staff that is on top of the situation every minute."

Keating says that the physicians and the staff need the sophisticated machinery behind them, but he emphasizes that the machinery does not take care of the patient. People do.

"It's the people that make the difference," he says. "Careful monitoring by machine is, of course, terribly important for the Reye syndrome patient. But it's the people who react to the machinery. Mechanization will never replace the people in medicine, especially when dealing with children."
The birth of conjoined twins has always fascinated both the lay person and physician alike. It is a rare event, even though the exact incidence of conjoined twins is not known. It is estimated to occur from one in 25,000 births to one in 80,000.

The best known term for this anomaly is "Siamese twins." P.T. Barnum promoted the exhibition of Chang and Eng Bunker, who were conjoined twins born in Siam in 1811. Many Siamese twins are born dead, but there have been more than 400 cases in which the twins survived, either joined or separated, from a few hours to 63 years.

Last summer the first Siamese twin separation surgeries to be done in St. Louis were performed at St. Louis Children's Hospital. The birth of the two sets of twins and the events which led up to their separation surgeries touched the personal and professional lives of many people.

The two sets of twins were born in December and March of 1977 and brought to Children's Hospital immediately for resuscitative surgery for intestinal obstruction. From the beginning, their cases were handled by Martin J. Bell, M.D., associate and Jessie L. Ternberg, M.D., Ph.D., professor and head of the Division of Pediatric Surgery.

One set of twins was transferred to the Ranken Jordan Home for a long period of time before their separation surgery.

The Reynolds twins returned to Children's Hospital to celebrate their second birthdays amidst the many friends they made during their stay here.
The other set had to remain at Children's Hospital because one of them had a difficult pulmonary problem based on a severe curvature of the spine.

Bell says this pulmonary problem was the catalyst which forced the separation surgery on the Hammond twins to be performed earlier than originally anticipated. "I felt we were endangering the life of the healthy twin by waiting," he says. "If the other twin were to die or suddenly deteriorate, the healthy one would be at risk since all of the dying tissue would be in contact with her bloodstream.

"On that basis we started planning last spring to do the separation earlier than originally anticipated. The surgery on the Hammond twins was scheduled first, with surgery on the Reynolds babies following two weeks later."

Even with the healthier set of twins, the separation surgery was deemed necessary because of the possible psychological problems they might develop from waiting. "We didn't know what effect an extended period of attachment would have on the girls," Bell says. "We have to assume there were psychological overtones with the separation even at a young age, but there would never be an adequate way to really evaluate the impact. In general, it must be believed that twins probably have some sort of deep-seated emotional relationship with each other."

It was also important to separate the twins for their physical, as well as psychological, development. Even though the twins did develop fairly normally while attached, they soon would have encountered problems with motor development. It would not have been possible for them to walk.

The healthier set of twins did devise a method of crawling by
using all of their extremities in what appeared to be synchronized effort.

"Movies were taken of the Reynolds babies while they were at the Ranken Jordan Home as they were becoming mobile," Ternberg says. "It was interesting to see how they worked as a team in order to move around. It was almost as if they were giving each other signals."

Ternberg and Bell agree that the staff at Children's Hospital and the Ranken Jordan Home did a tremendous job of working with the twins. "The twins grew up with caring people around them at all times, and they learned early how to relate to people," Ternberg says. "I feel the support staff is responsible for making the girls as socially responsive as they are now. So many people cared."

It was exactly this team effort among the physicians and support staff to which Ternberg and Bell attribute the eventual successful outcome of the separation surgeries. After the surgery dates were scheduled for last summer, a multidisciplinary team was formed and remained the same for both surgeries.

In the planning stages, Ternberg says the pediatric surgeons and radiologists worked closely together. Later on, specialists from anesthesia, urology, orthopedic surgery and plastic surgery joined the team. The nursing support staff was also an active part of the team.

"We had many, many planning conferences," Bell says. "There was considerable investigation of the babies' anatomical juncture; a lot of x-ray studies were prepared and studied by the pediatric radiologists and urologists. When all of our information was assembled, we had a medical illustrator draw a lot of the anatomy for us to help us visualize the task ahead of us. We then had conferences attended by everyone who was to be involved with the surgery. We attempted to plan our surgical strategy before surgery was ever begun."

Surgery to separate Siamese twins had never been performed in the St. Louis area, and it is not that common anywhere because of the low occurrence of conjoined twins. Bell says the team members did consult what limited literature there is on the subject. "Both sets of our twins were joined across the pelvis," he says, "which is among the least common types of junction. Even though this particular type of joining has had prior successful separations, most of the twins have died."

Bell and Ternberg both agree that the main lesson they learned from the separation surgeries was the importance of detailed advance planning. "Preparation is the key word," Bell says. "It is terribly important to gain as much anatomical information as possible and set aside considerable time for the surgery."

The two separation surgeries were performed on a Saturday to avoid as many other obligations as possible. Bell says the team had planned so long that the actual surgery was almost anti-climactic. But the day of the surgery was one of intense emotions, and a day that was not without surprises.

As she was operating on her set of twins, Ternberg discovered that the spinal cord ran across the juncture of the twins, something which had not been evident from x-rays. "We had no indication of this ahead of time," she says. "In all of my reading in the literature, I had only encountered this problem one other time. It had been discovered at autopsy and cited as a reason why those particular conjoined twins could not be separated."

The two separation surgeries, performed within two weeks of each other, lasted between fifteen and seventeen hours. With both sets of twins, two hours were spent in the operating room arranging the required monitoring apparatus. Each baby had two anesthesiologists. "Since the twins shared the same..."
vascular system," Ternberg says, "it was important for us to monitor the amount of fluid each was to receive."

The surgical team also used a unique operating room in that it has two operating tables and two overhead lights. "We wanted to use this so we could move the babies to individual tables after separation," Ternberg says.

The surgical procedure was divided into three major parts: separation of the muscular skeletal system, visceral separation and closure. The gastrointestinal and genitourinary tracts also had to be separated as well as separation of all the major vessels. "Each child ran one ureter to one bladder," Ternberg says, "and one of our major problems was to identify which bladder was going to be given to which child."

"The reconstructive aspects of the urologic and gastrointestinal orifices was another delicate procedure," Bell says. "Each child was given an ostomy for fecal diversion which will probably be permanent.

Closure of each child was also of major concern to the surgical team. "We had the plastic surgeons look at the situation and see what might be done with skin flaps," Ternberg says, "but fortunately they weren't necessary.

From the moment the two sets of conjoined twins were brought to Children's Hospital, Ternberg and Bell say there was never any question in their minds that the separation surgeries would one day be attempted. "We knew the risks were high and we made the parents aware of this at the outset," Bell says.

Three of the four twins have survived; it is felt that the one who did not would not have survived even if the surgery had never been attempted. "She was weak from the beginning," Bell says.
“and it was possible for her twin to have been seriously affected by her deterioration.” Obviously the quality of life for the young children has greatly improved since the surgery, even though all of them are going to require some further reconstructive surgery.

All of the girls will need vaginal reconstruction, a urinary diversion and further orthopedic work,” Bell says. “All of this is expected to be done by school age and the primary concern now is keeping their urinary tracts from becoming infected. All of their internal reproductive organs appear to be normal and one can anticipate a reasonably normal life for them.”

Bell and Ternberg agree that the twins had surprisingly uncomplicated post-operative courses. “There was very little difficulty during that period,” Ternberg says, “which I think is a tribute to all of the planning that went into the surgery and the care and expertise of the people involved. Performing this surgery and the resultant outcome was really rewarding. This kind of thing just doesn’t happen very often in one’s life!”

There is no predictable course to follow during surgery to separate conjoined twins. Each separation procedure is totally unique. Ternberg and Bell feel this is true of most situations encountered in the field of pediatric surgery. “I’m sure this is one of the things that attracts those of us in the field to the specialty,” Ternberg says. “The surgeon needs to be creative.”

This ability to be creative and deal with unusual, and many times sudden, complications is especially important in the field of pediatric surgery. “It’s especially important for us to possess,” Bell says, “because children, infants in particular, are a somewhat different species from adults. Their reaction to illness is different in so many respects simply because their physiology is immature. The difference between a ten-year-old and an adult is mostly size. But in the first year of life the differences are qualitative as well as quantitative. The physiology is so different in an immature human being that many of the things we do are different from adult surgery.”

The time span of an illness is also different in a child. Most of us with our own children know the degree of swiftness with which a young child can become ill. Fortunately, the young child also recovers quite rapidly. “This is based on real metabolic differences,” Bell says.

This rapid activity of childhood contributes to one of the awards of being a pediatric surgeon. “Even though we do have our share of chronically ill patients,” Bell says, “usually the recovery rate for children is quite fast. For those of us in surgery who demand immediate gratification for our efforts, this fast recovery rate really helps.”

Ternberg says another difference in caring for younger patients is the amount of time involved in that care. “When dealing with an adult patient,” she says, “it is possible to write out 24 hour orders and not worry. It’s very difficult to do that with an infant; much more time and patience is necessary.

“Surgery on an infant can also be more trying because the tissues don’t have the same strength as an adult’s. I once told
someone that operating on a really tiny preemie is rather like operating on wet tissue. Even with the smaller instruments used in pediatric surgery, it is an extremely delicate procedure.

The pediatric surgeon encounters a wide variety of clinical situations. There is a broad range of what might be called general pediatric surgery in which the surgeon deals with such problems as appendicitis, hernia and pyloric stenosis, the most common reason why a baby would require surgery. The pediatric surgeon must deal with these more common problems as well as the unusual situation which a Siamese twin separation surgery presents.

"W e also see a lot of congenital abnormalities that are life-threatening and must be operated on immediately," Ternberg says. "Oftentimes we perform a temporary procedure in a newborn in which further surgery will be necessary as the child becomes older. But we always have to think what the permanent solution will eventually be; we don't want to burn any bridges by doing an improper temporary procedure."

The pediatric surgeon must be creative, able to deal with the rapid clinical changes characteristic of the young child. He must also be empathetic to the needs of parents as well as their children.

"When you work with children," Ternberg says, "it's great when you win and very, very hard when you don't. And it's not just from the children themselves; an empathy is always developed between the parents and the physician as well. When you really care about what you're doing, then you begin to care about the family as a total unit, not simply the child."

Bell and Ternberg are very sympathetic with the parents of their patients because they realize what a difficult thing it is for a parent to turn their young child over to surgery. "It would be much easier to give permission to operate on yourself," Ternberg says. "That's one thing we always have to keep in mind when dealing with parents. One can't go into the field of pediatric surgery and lack compassion. This ability to be understanding is just as important to the pediatric surgeon as the ability to make immediate decisions."

The pediatric support staff, as well as the physicians, must also possess a caring, empathetic personality. The support staff becomes a surrogate family, especially to the infant who must spend the early months of his life hospitalized. Caring for an infant also requires more support staff in order to provide a nurturing environment.

"This is the difference between the care one receives at Children's Hospital and the care at an adult hospital. In an adult hospital, no one on the staff becomes a surrogate family," Bell says. "We make every effort to help the parents through an emotionally charged time, and the nurses are especially attuned to their needs from having the most contact with them."

The clinical situations seen in pediatric surgery, such as the twin separation surgeries, are dynamic and provide the pediatric surgeon with a great deal of personal satisfaction and occasional heartache. Ternberg and Bell both say their affiliation with the staff at Children's Hospital adds to this satisfaction, both personally and professionally.

"The caring, concerned people here at Children's Hospital have made it what it is," Bell says. "It's no wonder the tremendous strides in pediatric care have been made here."

Both Ternberg and Bell love what they do. "I enjoy all aspects of it," Ternberg says. "The scientific puzzles, the relationships with the kids and their families. The only rough part is when we lose, and we're always trying to figure out what we can do differently the next time. This is what motivates those of us in pediatric surgery. We are all involved in clinical research, driven to the problem by what we've seen."

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Jessie L. Ternberg, M.D., Ph.D., professor of and head of the Division of Pediatric Surgery.
Introducing 1979 Nobel Laureate Daniel Nathans, M.D. '34

President-elect Robert C. Drews, M.D. '55 and President John F. Bergmann, M.D. '54
Our 50th Reunion

The 50th reunion of the Class of '29 came off in great style. Our thanks to Claire MacConnell, Director of the Medical Center Alumni Office, and her associates Ruth Moenster and LaVerne Kammer, whose careful planning of events made everything run smoothly. Our thanks also to our gracious hosts, the Administration of the Medical School, and the Medical Alumni Association.

When this class of 74 members graduated in June of '29 there was no reason to think of anything but a peaceful and prosperous world to conquer. St. Louis, along with the rest of the country, was experiencing rapid growth in business expansion and building construction until the Great Depression hit in the early Fall of '29 and brought about profound changes. Perhaps the Depression did not affect us as much as it did the community in general since we were leading a cloistered life in internship and residencies. Eventually we had to go out and start practice in a harsh world; conditions did finally improve but then came World War II to disrupt our lives again. Two of our members, Hans Kleine and Armin Leuschner, were not to return.

In many ways, these 50 years have been hard, but time, they say, heals all things. The 22 members of the class who attended the reunion are a vigorous and happy group who, in different ways, have achieved their goals. Some are still active in practice. Thirty-six members of our class are living.

Festivities began with a welcoming cocktail party at the McDonnell Basic Sciences Building in the medical school complex. It was a great party for renewing old friendships. Our class party at the Whittemore House was the highlight of the reunion. It was a time for reminiscing. Dr. Mildred Trotter, Professor Emeritus of Anatomy, was our honored guest. She is a delightful person and we are very happy that she accepted our invitation.

Dr. John Bergmann, President of the Medical Alumni, presided at the banquet. He introduced Guerdan Hardy who responded for our class. His address was just right: thoughtful with good advice to the graduating class. We are very proud of him. We would be remiss if we failed to acknowledge the hard work of the Women's Committee, headed by Mrs. John Bergmann. The wives enjoyed their tours and shopping sprees.

The memory of this very special affair will be cherished.

James M. Macnish, M.D.
Reunion Chairman-Class of '29
45th Reunion — Class of 1934 — May 3, 1979

40th Reunion — Class of 1939 — May 3, 1979
Seated: Drs. Nuttall, Bernard, Ackerly.
Standing: Drs. Corgill, Beasley, Epstein, Towers, Melick, Harrell, Reinhard, Hall, Baumgarten, Cockett, Fox, Bierman.
35th Reunion — Class of 1944 — May 3, 1979

Seated: Drs. Murfin, Farginstein, Cox, Pollock.

30th Reunion — Class of 1949 — May 3, 1979

Second Row: Drs. Innes, Jick, Bumgarner, Gray, Norsa, Peterson, Whitmore.
Fourth Row: Drs. Shelden, Hult, Carleton, Smith.
25th Reunion — Class of 1954 — May 3, 1979
Seated:  Drs. Bergmann, Freiermuth, Bauer, Nathans, Arditi, Rosenbach, Mendelsohn, Langdon.

20th Reunion — Class of 1959 — May 3, 1979
15th Reunion — Class of 1964 — May 3, 1979
Seated: Drs. Hembree, Evens, Friedman, Crane.
Standing: Drs. Manske, Allen, Teitelbaum, Hardy, Cheuk, Rawson, McCown, Reinhardt.

10th Reunion — Class of 1969 — May 3, 1979
Kneeling: Drs. Dowell, Barr, Kolodny, Goodman, Siegel.
Seated: Drs. Hall, Krajcovic, C. Smith, Fathman, Blatt.
Alumni Banquet

James F. Zakem, M.D., President, Class of '79

Medical School Legacies: James W. Owen, III, M.D. '79, James W. Owen Jr., M.D. '46, David A. Hardy, M.D. '64, Guerdan Hardy, M.D. '29, Robert H. Lund Jr., M.D. '79, Robert H. Lund, M.D. '49

Class of 1929
Class Notes

'30s

Delevan Calkins, '31, Pompano Beach, FL, was presented to the Queen and the Duke of Edinburgh at St. James Palace last summer.

William W. Herman, '33, Shaker Heights, OH, retired as assistant professor emeritus of pediatrics at Case Western Reserve University Medical School.

Joseph C. Jaudon, '33, St. Louis, celebrated his 50th wedding anniversary Dec. 12. Congratulations Dr. and Mrs. Jaudon.

Augustin Jones, '35, St. Louis, scientific exhibit won honorable mention at the Southern Medical Association in November.

L.G. Pray, '35, Palm Desert, CA, is enjoying his retirement and part-time work as a pediatrician for the Riverside County Health Department.

V. Terrell Davis, Jr., '36, is director of the Department of Psychiatry at the Wilmington Medical Center in Delaware. He also is consultant to the Division of Mental Health Service Program of the National Institute of Mental Health.

William H. Jacobson, '36, Palm Springs, CA, has come out of retirement and is serving as consultant at the Riverside County Methadone Clinic on a part-time basis.

Roland S. Bassman, '37, St. Louis, retired from private practice but is engaged in practice at the out-patient clinics of St. Louis County and Missouri Pacific Hospitals.

A. Alfred Golden, '38, Toledo, has retired.

T. Eugene Ruff, '38, Poplar Bluff, MO, retired from the Knesbirt Clinic last year.

William F. Melick, '39, St. Louis, was named president of the American Urological Association.

Arnold D. Welch, '39, Memphis, was honored on his 70th birthday with a special issue of "Biomedical Pharmacology." Dr. Welch is one of the early founders of the journal, and has made many contributions to the scientific field which it represents.

'40s

Roland R. Cross, '40, is professor and chairman of the Department of Urology at Loyola University Stritch School of Medicine. Last July Dr. Cross was made acting associate dean for staff at the School and chief of staff for the McGaw Hospital.

Thomas S. Jackson, '41, has been in family practice in Clio, Ala., since 1947. He is past president of the Barbour County Alabama Medical Society and is the chairman of the Barbour County Board of Censors.

James H. Cravens, '43D, Quincy, Ill., was recently elected to the executive committee of the Illinois Chapter of the American Academy of Pediatrics.

Louis A. Gottschalk, '43D, Orange, CA, was awarded the Foundation's Fund Prize for Research in Psychiatry by the American Psychiatric Assoc. in 1978. Dr. Gottschalk is also professor of psychiatry and co-director of the Alcoholism Research Center, U. of California at Irvine.

Bruce W. Armstrong, '44, is Chief of Medical Service at the VA Medical Center, Walla Walla, Washington.

Wesley Fee, '44, since retiring three years ago is spending half his time in Alaska working as a volunteer for the Public Health Service at the Alaska National Medical Center.

Edward A. Mason, '44, is director of the Harvard Mental Health Film Program.

Robert D. Lange, '44, Knoxville, was named chairman of the newly formed Department of Medical Biology at the University of Tennessee Center for Health Sciences.

Melvin J. Johnson, '46, efforts in alcohol treatment have resulted in establishing a Rehabilitation Center at the Missoula Montana General Hospital. The Melvin Johnson Center is a multi-discipline concept which is used in treating the whole person. The percentage of sobriety is 75 to 78 percent.

James C. Sisk, '46, St. Louis, was elected Speaker of the Program Conference of Blue Cross Blue Shield. Dr. Sisk also is on the Board of Directors of Medical Indemnity of America, Inc., an insurance company based in Chicago.

Brig. Gen. Ernest J. Clark, '48, was awarded the Distinguished Service Medal at a USAF ceremony in Washington, D.C.

General Clark was cited for exceptionally meritorious service as Director of Professional Services, Office of the Surgeon General, Headquarters USAF, from April 14, 1975 to Oct. 31, 1978.

Edward Pinney, Jr., '49, New York, visited the Grand Cayman Island as a guest consultant on drug abuse for the National Council of Social Service as a part of their observation of the Year of the Child.

'50s

Marvin E. Levin, '51, St. Louis, was awarded the Pfizer Award for Outstanding Contributions to Clinical Medicine at the 39th Annual Meeting of the American Diabetes Association.

Grant Izmirlan, '51, is president of the St. Louis Academy of Family Physicians.

Francis C. King, '52, St. Louis, was certified in family practice last year.

Richard B. Windsor, '52, Sheboygan, WI, has been the sailing champion in the Laser class at the Elkhart Lake Sailing Club for the past four years.

Charles E. Brodine, '53, is the chairman of the Department of Preventive Medicine at the University of Illinois Chicago.

Herbert L. Winograd, '53, Phoenix, is the president of the Arizona Affiliate, American Diabetes Association.

Robert M. Leysie, '54, Bellevue, WA, was elected to the Pacific Coast Surgical Association.

Kenneth Shulman, '54, Bronx, NY, is the chairman of the Department of Neurological Surgery at the Albert Einstein College of Medicine.

Robert C. Drews, '55, St. Louis, was promoted to professor of clinical ophthalmology at Washington University School of Medicine. Dr. Drews also received an honor award from the American Academy of Ophthalmology and was named vice president of the Pan American Ophthalmological Foundation and the third vice president of the A.A.O.

Charles W. Markham, '55, Belle- aire Beach, FL, has joined the Diagnostic Clinic in Largo, Fla.

Dan B. Moore, '55, Sacramento, CA, is a surgeon with the Kaiser Permanente Medical Center, and was appointed the U. of California's first Blaisdell Professor of Clinical Surgery.

Col. Donald H. Tilson, '55, Vancouver, WA, has retired from the Army, and is working for Kaiser Permanente Medical Center in Portland.

John W. Drake, '56, Oklahoma City, was appointed by the Governor to the State Board of Mental Health.

Robert J. Hoehn, '56, Denver, is clinical professor of surgery at the University of Colorado Medical Center.

Col. Michio Kaku, '56, Carmel, CA, has retired from the Army.

Harriet S. Kaplan, '56, Rancho Palos Verdes, CA, is head physician of the Psychiatric Emergency Service at L.A. County Harbor/U.C.L.A. Medical Center.

William A. Reynolds, '56, Missoula, has been elected as governor of the Montana-Wyoming chapter of the American College of Physicians.

Paul L. Friedman, '57, St. Louis, is president of the Missouri Society of Anesthesiologists.

Donald E. Terry, '57, Wichita Falls, TX, was elected to fellowship by the American College of Cardiology.

Matthew K. Becker, '58, Orange Park, FL, has retired from the Navy and is entering private practice of general surgery.

William I. Goettman, '58, Springfield, OH, received the Class of '14 Award from Wittenberg University.

David L. Rahim, '58, Washington, D.C., is president-elect of the Association of Teachers of Preventive Medicine.

'60s

Charles W. Boren, '60, has been named Director of Medical Education at the Institute of Living, Hartford, Conn.

Robert E. Fechner, '60, has been promoted to professor of pathology and director of surgical pathology at the University of Virginia School of Medicine in Charlottesville.
Donald H. Finger, M.D.

practice in 1957 and quickly built a very large practice confined primarily to consultation in chest diseases. It is ironic that a pulmonary disease, emphysema, claimed his life.

Don was a member of the staffs of Barnes Hospital, Jewish Hospital and St. Luke's Hospital. He was Associate Professor of Clinical Medicine at the Washington University School of Medicine. He was a Diplomate of the American Board of Internal Medicine, a Fellow of the American College of Chest Physicians and of the American College of Physicians. He was a member of the American Medical Association, the Missouri State Medical Association, and the St. Louis Medical Society, and was editor of its bulletin.

Don was the complete physician. He was truly a doctor's doctor, having many physicians as his private patients, a great tribute to his ability. He was a counselor not only for his peers but especially for students, interns and residents. Over the years he was advisor and confidant to many house officers and students and played a major role in the future planning of their medical careers.

Don will be missed and long remembered by his many friends and grateful patients, but most of all by his son, John, now a law student at Michigan University, and by his loving and devoted wife, Doris, who generously and patiently shared him with his many patients and with house staff and students who always needed just another moment of his time for guidance and instruction which he gave so unselfishly and so frequently.

A very special person has left us but the memory of him will be with us forever.

Marvin E. Levin, M.D., '51

The medical profession has lost not only a superb physician but a great friend with the death of Donald H. Finger, June 21, 1979, at age 53. A large number of alumni will remember Don from his medical school days and especially as the President of the Alumni Association from 1974 to 1975. He had been very active in alumni affairs and played an important role in the organization and development of the Alumni Association Clinical Conferences. These have grown in popularity in size and attendance, thanks to Don's leadership and guidance.

Don graduated Washington University School of Medicine in 1950 and was a member of the Medical Honorary Society, AOA. He was an intern and assistant resident at Barnes Hospital, 1950-52, and in 1952-53 he was a Fellow in Pulmonary Disease at the Columbia University Chest Division at Bellevue Hospital in New York. He returned to Barnes Hospital in 1953 as Chief Resident. He entered private practice in 1955 but this was interrupted by a two year stint in the Armed Services as a Captain in the Air Force. During that time he served as a member of the Streptococcal Commission. He returned to private practice in 1957 and quickly built a very large practice confined primarily to consultation in chest diseases. It is ironic that a pulmonary disease, emphysema, claimed his life.

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In Memorium

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James H. Allison
Richard H. Ames, '35
Elbert D. Apple, '29
Elska Atkins, '05
William G. Baker, '38
Paul S. Barker, '20
Jacob W. Bergstrom, '18
Bertram J. Bouquet, '31
Bert M. Bullington, '35
J. Paul Burgess, '30
James W. Burks, Jr., '37
John Caffey

Howard T. Robertson, '40
Lee R. Swan, '64
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Frederick O. Schwartz, '10
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