

# brainPOWER

St. Jude provides leadership for national brain tumor consortium.

By Victoria Tilney McDonough

James Boyett, PhD



ANN-MARGARET HEDGES

Anyone who has ever helped a kid with a science project knows the importance of conducting a well-designed and carefully executed study. Pretty pictures and clever display boards will not yield that coveted A+; the youngster must first keep scrupulous records and engage in some elementary statistical analysis.

Scientists seeking cures for tumors of the central nervous system know the importance of creating innovative studies backed by high-quality statistical science. Under the leadership of St. Jude Children's Research Hospital, a prestigious group of hospitals and research institutions are working together to do just that.

St. Jude is the operations and scientific center of the Pediatric Brain Tumor Consortium (PBTC), which was formed by the National Cancer Institute in 1999. Most children with primary brain tumors in the United States go to St. Jude or one of the other nine PBTC institutions for diagnosis and treatment. These institutions pool their intellectual resources and statistical data to identify superior treatments for children with brain cancers and to further understand the biology of central nervous system tumors. Larry Kun, MD, chair of St. Jude Radiological Sciences, leads the PBTC steering and scientific committees.

Before the PBTC was conceived, James Boyett, PhD, chair of St. Jude Biostatistics, saw the need for a central location from which to manage millions of pieces of data. To coordinate the activities of institutions spread across the nation, he developed an Operations and Biostatistics Center for the PBTC. Boyett first became interested in multi-

center trials back when computers were the "size of refrigerators and as slow as Christmas." Today he serves as principal investigator of the PBTC and executive director of its high-tech nerve center, the Operations and Biostatistics Center.

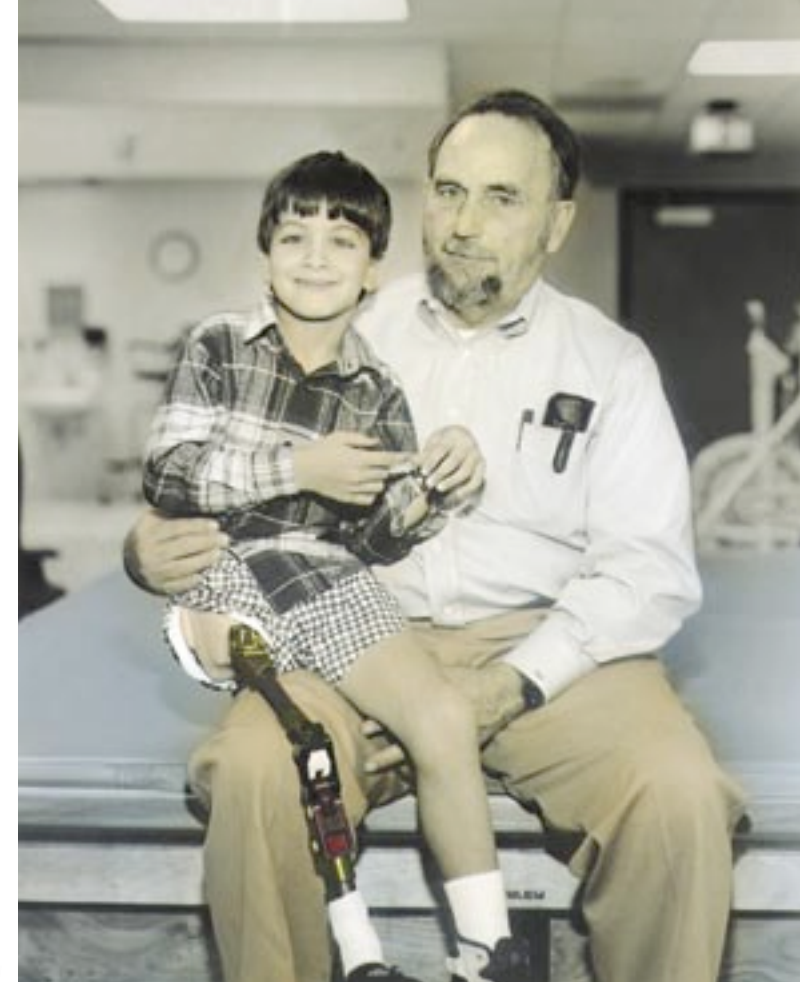
Boyett and his team have created a secure electronic means of moving neuro-imaging files. "These are huge, encrypted files," he says. "We collect them from the PBTC institutions and send them to the physical neuro-imaging center established at Harvard, where they are evaluated. This technology has allowed us not only to collect pictures but also to collect the data behind them and to do it all electronically."

Operations and Biostatistics Center staff members also masterminded a novel data transfer system that ensures smooth collaboration. "We've established a nearly paperless multi-center data management system where all the PBTC hospitals have laptops with software we've created and set up to securely collect the protocol data for analysis and reporting," Boyett says.

All of these technological advances help scientists take the methods they learned in elementary school to a higher level. "A protocol arises from a question," Boyett explains. "It's up to us to figure out how best to answer that question. First and foremost, the study has to have a good statistical design so that patients who consent to participate in the research truly contribute to a better understanding of these diseases. From there, it must be conducted to a T so as to get as close as possible to answering that question."

Thanks to St. Jude leadership and collaborations, scientists studying brain tumors are moving ever closer to cures. And that rates an A+ for sure. ●

JOHN ZACHER



St. Jude patient Ryan Zimmerman sits on the lap of Ronney Snell, who made prosthetic devices for children at the hospital and helped establish the institution's Rehabilitation Services department. "Mr. Ronney was Ryan's hero," says Ryan's mom, Marilyn. Snell's friends and family have created a \$50,000 endowment in his memory.

In the early 1960s, at a time when survival rates for childhood cancer were slim and the most common treatment for solid tumors was amputation, the late Ronney Snell made prosthetic devices for the children of St. Jude Children's Research Hospital. As the third generation in his family to enter the field, Snell believed in caring for the child as a whole and did his best to restore a sense of normalcy to young patients.

"Ronney specialized in helping children," says his wife, Karrene. "His philosophy was to heal the child of the illness and help the whole child in the process. He wanted them to feel normal even though they may have lost a limb."

Snell's relationship with St. Jude began when he started providing prosthetic devices for children with osteosarcoma, the most common form of bone cancer in children and adolescents. Snell not only developed the parts, but he also taught the patients how to get the most efficient use from the devices. His dedication to the children grew deeper through the years.

"St. Jude was his love, and his compassion and love for the children motivated him to do his job every day," says Karrene. "As his family, we understood that love and grew to love the hospital as well."

## Putting Children First

By Alicia H. Matthews

Snell made it clear that he always thought of the child first when designing a prosthetic device.

"When Ronney was with a patient, that child knew that 'Mr. Ronney' was focused on him," says Lola Cremer, director of Rehabilitation Services. "No matter how severe the disability, the image reflected back to the child was one of wholeness. I never saw Ronney fit a brace or a prosthesis without considering carefully what that device would allow the child to do that he couldn't already do."

Snell's legacy pervades the hospital's Rehabilitation Services department, which he helped establish. In honor of his commitment to St. Jude patients, Snell's friends and family dedicated a \$50,000 endowment in his name to the hospital—the Ronney Snell Memorial Fund.

"Ronney loved to fly, and he loved to sail," recalls Cremer. "He was continually looking up and declaring it a good day for one or the other. He taught me to look up to see the big picture—to focus on the difference that could be made in the life of a child...for that is all that really matters. He taught us all to 'adjust the sails' to take children where they needed to go." ●

**He restored a sense of normalcy to countless St. Jude patients.**

**Now Ronney Snell's legacy continues with an endowment to Rehabilitation Services.**

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