The goal has always been to improve treatment so that more children would live and grow up with as few late effects as possible. Today 90% of children diagnosed with Wilms tumor survive, and we are continuing to collect information to see if we have eliminated many of the late effects that had previously been observed and to detect any effect treatment might have in the next generation.

A major purpose of the NWTS Late Effects Study is to answer the question asked by NWTS participants who are now parents: Will my children be at a higher risk of having health conditions present at birth or developing them later?

We now must try to answer this question: Has the chemotherapy and radiation therapy used in modern treatment caused changes in the eggs and sperm which might lead to an increased chance of developing Wilms tumor or serious birth defects in their children? Scientists already believe that about 10% of Wilms tumors are caused by certain genetic mutations. Mutations occur naturally in all dividing cells. The complicated genetic changes resulting in the passing down of any mutation to yet another generation is even rarer. Accurately counting how often these rare events happen in the children of those who have been successfully treated for Wilms tumor is very important.

So far, we have not collected nearly enough information to answer these questions, but recently we began to systematically collect information about these births and to regularly ask about the growing children in order to monitor their health. Sixty years ago children with Wilms tumor did not often survive to grow up and have their own children. Since then radiation therapy helped more children survive, but at first left many of them unable to have children themselves. Now, with modern treatment, including lower doses of radiotherapy, most children survive Wilms tumor and are able to become parents.

From October, 1969 through May, 2002, we completed five clinical trials for the treatment of newly diagnosed Wilms tumor—each trial building on the results of the one before to improve treatment outcome. Each trial tried to identify which patients needed more treatment to survive and which could survive with less treatment and consequently with fewer late effects. There is no “one best treatment” for Wilms tumor because treatment depends on many factors including extent of disease, cell type, age at diagnosis, and the size of the tumor. With each new trial, effective treatment for most patients included lower doses of radiotherapy and chemotherapy over shorter periods of time. The goal has always been to improve treatment so that more children would live and grow up with as few late effects as possible. Today 90% of children diagnosed with Wilms tumor survive, and we are continuing to collect information to see if we have eliminated many of the late effects that had previously been observed and to detect any effect treatment might have in the next generation.

Many physicians advise physical restrictions on children who have only one kidney whether it is a condition the child is born with or acquired after surgical removal of a kidney. The American Academy of Pediatrics (AAP) has published recommendations regarding sports participation for children with medical conditions. They state that children with a single kidney need individual assessment for contact, collision, and limited-contact sports. They do not recommend participation in boxing and suggest only a limited amount of body checking for hockey players 15 years and younger. Sports with high contact/collision potential include football, martial arts, rugby, rodeo, basketball and wrestling.

A review of 49,651 patients reported to the National Pediatric Trauma Registry from 1996-2001 identified 813 renal injuries of which only 85 were due to sports. (None of these injuries occurred in a patient with a solitary kidney, but this is likely due to the rarity of this condition.) The most common sports injuries were due to football, followed by sledding, snowboarding, skiing, skateboarding. Of interest, renal trauma due to bicycle injuries was more common than sports related injuries. Bicycling is considered a limited contact sport. The most common cause of renal injury in both children and adults is a motor vehicle accident. Although the risk of renal injury from sports is low, children with a solitary kidney who participate in contact sports should consider protective equipment. A number of products are now commercially available, e.g. TKO kidney protector, and WIS-Wikmax kidney protection shirts.


BREASTFEEDING SURVEY

Female participants who have had the joyous experience of welcoming a baby into their lives will soon be receiving a questionnaire asking about their experience with breastfeeding. We believe it is important to know if treatment for Wilms tumor has any effect on breastfeeding, but we have been unable to find any research on this topic. For those of you who receive this questionnaire, we would greatly appreciate your taking the time to complete and return it at your earliest convenience. Thank you in advance for your cooperation with this aspect of the study.