

LATE BREAKING NEWS

from the **National Wilms Tumor Study**

“A Real Story” Insurance Coverage for a Late Effect

Jocelyn Reall was only seven years old in 1999 when she was diagnosed and treated for Stage 4 Wilms Tumor. Her treatment included radiation to the chest. The Realls suspected she might have complications with breast development, but they gave her body time to develop on its own. By her eighteenth birthday Jocelyn had almost no breast development, and the family sought correction for her.

In June of 2009, Akron Children’s Hospital, where Jocelyn had received her treatment for Wilms Tumor, responded to an inquiry from the Realls and told them about a young, local woman who received breast augmentation for a similar situation. Encouraged, they pursued augmentation surgery for Jocelyn, submitting a claim to their insurance company based on the fact that her complications were late-effects therapy-related. The claim was immediately denied. The company said the procedure was cosmetic and denied by the policy. The Realls argued Jocelyn’s case was no different than a mastectomy survivor who needs reconstructive surgery. Their claim continued to be denied on the basis that the procedure was cosmetic.

In September 2009, the Realls contacted the company requesting a second level review. They learned their first appeal was made too late—they had sixty days to respond—and they had to start the appeal process all over again. They often received conflicting information from the insurance company about how much time they had to appeal the case.

That same month, the family heard about a young California woman and a Canadian woman who had similar experiences, and they contacted the NWTS hoping for information about the cases. Confidentiality precluded the NWTS from putting the parties in contact with one another, but they did put the Realls in touch with Grace Monaco, a Childhood Cancer Ombudsman Program Advocate. Her advice was to obtain a letter from a cosmetic surgeon recommending the operation to re-establish normalcy. They also submitted copies of the letter to both Ohio state senators and the president of the insurance company.

In November 2009, Senator Sherrod Brown’s office responded offering assistance. They contacted the Consumer Advocate at the insurance company as well as the Ohio Department of Insurance. The Realls missed a “seven day window”; appeal denied. The appeal process would have to start all over again. They believed they had sixty days and after many calls to the company, the Realls talked with a company official who agreed to assign the appeal to expedited review.

On December 11, 2009, the company informed the Realls that their case was on expedited review. Jocelyn’s surgery was scheduled very soon, and a resolution was imperative. The company told them that the review, which could take up to fifteen days, was scheduled for December 14. On December 14, the company requested more

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information, and the next day the Realls were told that the company's Medical Director denied their appeal and transferred it to a Second Level Hearing via teleconference, with the Realls having the option of having three people to represent them. Their team included the Realls, Jocelyn's plastic surgeon and her pediatric oncologist. The Realls requested that the company's team include an expert in pediatric oncology.

The December 21 teleconference lasted fifteen minutes, with all members of the Realls' team making statements and the three company representatives choosing not to make any statements or ask any questions. One-half hour later the Realls received a call: the company acknowledged Jocelyn's late effect of radiation therapy; her breast augmentation was approved and shortly thereafter she had a successful operation.

The Realls' persistence was essential to Jocelyn's ultimate successful outcome. The NWTS would like to thank the Realls for sharing their story, Grace Monaco for pointing them in the right direction, and many others who saw the importance of Jocelyn regaining normalcy. We know that some childhood cancer survivors can face high hurdles in achieving goals such as the Realls sought. We cannot promise you success, but we can promise to make all of our resources available to you to make the journey as easy (and hopefully as successful) as possible. ■

What to Do If You are Uninsured

by Gib Smith, JD – Director of the Childhood Cancer Ombudsman Program and Grace Powers Monaco, JD, Consultant to the Childhood Cancer Ombudsman Program

Access to care is compromised when a family member is uninsured. What can the medical care team do to help cancer patient/survivors and their families find health insurance? This is a real and constant problem in the cancer community. It is tough enough trying to recover from chemotherapy and radiation blasts without having to worry about how to pay for these necessary treatments and dealing with preexisting condition exclusions. This article attempts to provide a brief overview of some of the resources and protections available to the uninsured affected by a diagnosis of cancer. If you are a survivor or cancer patient and uninsured we can suggest the following resources/options:

CONTACT YOUR COUNTY WELFARE OFFICE

Call your County Welfare Office and ask for information about applying for Aged, Blind, Disabled Medically Needy Medicaid for your child. If you meet the income and asset limits, your child can be put on Medicaid.

While on the phone with the welfare office, ask them to check on the Children's Health Insurance Program [CHIP]. In 1997 the SCHIP Program gave the states new federal funds to expand children's health coverage programs, which led to a dramatic extension of coverage for low-income children through Medicaid and separate SCHIP programs. The program is now known as CHIP; please see <http://www.cms.gov/home/chip.asp>.

CONTACT SOCIAL WORKER IN PEDIATRIC ONCOLOGY CLINIC

An underutilized excellent source of information regarding local resources is the social worker in the pediatric oncology clinic. For example, in some facilities, Social Security employees come to the hospital periodically to help families apply for benefits. The social worker should have contact information so you can apply for the right welfare programs.

CONTACT STATE'S CHILDREN'S MEDICAL SERVICES PROGRAM

Check on resources of your State's Children's Medical Services Program. Some families who don't qualify for Medicaid may qualify for assistance to pay for needed care under that program, if the family income level is below their coverage income level.

VISIT HIPAA WEBSITE

Consider the Health Insurance Portability and Accountability Act [HIPAA], which allows those with preexisting conditions to secure comprehensive health insurance coverage. From the parent's perspective, HIPAA also helps people maintain their coverage if they need to change insurance or jobs. For more information regarding HIPAA visit <http://cms.hhs.gov>.

CONTACT U.S. DEPT. OF LABOR'S PENSION & WELFARE BENEFITS OFFICE ABOUT COBRA

The Consolidated Omnibus Budget Reconciliation Act [COBRA] mandates that both public and private employers with twenty or more employees for greater than 50% of the working days in the previous calendar year, must make insurance coverage available for a limited period of time to employees and their dependents. Under COBRA, employees who have been fired or laid off have a right to continue their group health coverage at their own expense at no more than 102% of their employer's group rate. For those individuals with disabilities, the coverage period can be extended to 29 months in certain situations. For further information regarding COBRA, contact the Pension and Welfare Benefits administration at the United States Department of Labor.

VISIT CONSUMER HELPLINE TO LEARN HOW PPACA EXPANDS HEALTH CARE COVERAGE

Finally, the Patient Protection and Affordable Care Act [PPACA], signed into law on March 23, 2010 seeks to expand health care coverage to all uninsured Americans. Some of these provisions are already in effect as follows:

1. Effective July 12, 2010 – Implementation of the requirements in Section 1001 of PPACA for group health plans and health insurance coverage in the group and individual markets allowing dependent coverage of children who have not attained age 26.
2. Effective August 27, 2010 – Implementation of the rules for group health plans and health insurance coverage in group and individual markets eliminating pre-existing condition exclusions for children, eliminating lifetime and annual dollar limits on benefits, eliminating rescissions and improving patient protections through the implementation of internal and external appeal processes.

For a complete list of the PPACA provisions and their related implementation timelines please see <http://healthreform.kff.org/the-basics.aspx>.

PPACA also features other helpful provisions including: the ability to purchase coverage through insurance exchanges with premium and cost-sharing credits available to some people to make coverage more affordable; incentives for employers to offer insurance; rules preventing insurers from denying coverage due to health condition; and expanding the Medicaid eligibility for families and individuals under 65.

It is important to know and understand your rights under PPACA. There are lots of resources via PPACA that are available to help the uninsured find insurance coverage. The Center for Consumer Information and Insurance Oversight (CCIIO) (<http://www.hhs.gov/cciio/index.html>) is responsible for implementing many major provisions of PPACA and features a consumer helpline at <http://www.healthcare.gov/>. ■

BREASTFEEDING SURVEY

We would like to take a look at whether breastfeeding is affected by Wilms tumor (WT) treatment. While we have no information that would make us believe that treatment of WT affects a young woman's breastfeeding experience, we would like to learn more about our participants' experiences. Some of you replied to a pilot survey that we sent out several years ago. Thank you. Now we will send out a survey to a larger group of mothers to learn more. The Breastfeeding Survey will also be on our website and you can complete it using Survey Monkey. If you have not reported to us that you have had a child or you now have additional children, not previously reported, please complete an Annual Status Report form on our website, www.nwtsg.org, or call **1-800-553-4878** to report the new birth(s). Thank you.

A LITTLE LATE

This year our newsletter is later than usual, but we hope that it provides you with new and helpful information. This delay resulted from our efforts to submit an application to the National Institutes of Health (NIH) for another five years of funding.

Forty-two years ago last October, the first participant was enrolled on the first NWTS clinical trial. By the time the fifth and last clinical trial ended in 2002, families had agreed to enroll nearly 10,000 children with us. We cannot thank you enough for your trust.

We have been continuously funded by NIH since 1969, making us one of the longest running research groups in the nation. Our current application faces stiff competition, but we hope for a successful outcome. When we know the results we will post a notice on our website. In the meantime, thank you all for your support and for your contributions to our many successful years, and hopefully, many more to come.

Dr. Panayotis Kelalis

by Michael Ritchey, M.D.

We occasionally take the opportunity to recognize past members of the National Wilms Tumor Study Group and their contributions to the study of Wilms tumor. We here remember Dr. Panayotis (Panos) Kelalis. The NWTS was a multidisciplinary group including medical oncologists, pathologists, radiation oncologists, epidemiologists, statisticians and surgeons. The latter included both pediatric general surgeons and pediatric urologists. Dr. Kelalis was the third pediatric urologist to become a member of this esteemed group in 1984, succeeding Doctors Willard Goodwin and Lowell King.

Dr. Kelalis spent his entire professional life at the Mayo Clinic in Rochester, MN. He obtained his medical degree at the University of Dublin in Ireland and then completed urologic training at the Mayo Clinic in 1964. He established the pediatric urology department there, and developed one of the early fellowship training programs in that specialty.

Participation in multidisciplinary committees requires many important attributes to be successful. Panos had all of them: compassion, collegiality, curiosity and commitment. In this modern age, much of the committee work is done electronically and via conference calls. Data can be stored and accessed via remote servers. However, the work of the committee in the earlier years required the members to travel to the Data and Statistical Center in Seattle to review patient charts. There were many hours of detailed work, but it afforded the members an opportunity to gather and discuss the progress of the studies and plan future research initiatives. Many members developed close personal friendships and professional relationships lasting for decades.

Dr. Kelalis spent his entire career as an educator and trained many urologic residents and fellows. His interest in Wilms tumor brought attention to this disease. Many of his trainees soon became involved in research projects involving the surgical care of children with this malignant renal tumor. Dr. Kelalis' particular concern was the care of children with bilateral Wilms tumor and how to avoid bilateral nephrectomy. He was also concerned about the surgical risks of removing large tumors and was determined to identify strategies to limit surgical morbidity.



Dr. Kelalis passed away in 2002. His legacy endures as physicians he trained remain involved with the study of children with Wilms tumor. I had the privilege of succeeding Panos on the NWTSG committee in 1992. Over the years, Panos and those he mentored and stimulated have authored or co-authored more than 100 papers and textbook chapters on Wilms tumor. His important contributions to the care of children with this disease will long be remembered, and our memories of him as a mentor, friend and colleague will endure even longer. ■

Planning the First National Wilms Tumor Study

by G.J. D'Angio, M.D.

The National Wilms Tumor Study (NWTSG) was launched as the first intergroup national study including representatives of all pediatric cancer study groups. It was also the first that focused on the “solid” tumors of childhood (the malignant diseases other than the leukemia/lymphoma types). Moreover, it was envisioned as an interdisciplinary research project including surgeons, urologists, chemotherapists, and radiation therapists.

The NWTSG was quite unique in its structure. The first Chairman had been taught to consult a statistician before initiating any research project and had done so for his laboratory studies. It seemed no less wise to apply that principle to clinical research; even more, to have that specialist not as a consultant, but as a full, voting member of the NWTSG Committee (NWTSC). That was done. Too often before, clinical research data were accumulated and then handed over to others for review and statistical evaluation—only to be found wanting. Dr. Norman Breslow has been the NWTSG statistician since its beginning.

A pillar of any research project is the quality and accuracy of the information collected. First in a clinical study is the accuracy of diagnosis. To insure that all diagnoses were correct, a Central Pathology Review Center staffed by an expert pediatric pathologist was created. All specimens would undergo central review so that inaccurate diagnoses could be eliminated. In the process, the review pathologist, who also was made a full, voting member of the NWTSC, would gain experience and expertise. This would allow that person to conduct separate but parallel investigations into the nature of the kidney cancers of childhood, which was one of the NWTSG goals.

Another pillar of research is the accurate handling of relevant data. Therefore, a central NWTSG Data and Statistical Center (DSC), under the guidance of the statistician/epidemiologist, was created. When you receive requests for information on your health or your contact information, these are sent by the staff of the DSC. The DSC is also responsible for making every effort to keep the data safe and confidential. The statistician in charge, like the pathologist, could also utilize the experience, expertise, and the gathered information to mount parallel investigations.

Those organizing the NWTSG were interested not only in the survival outcomes of the various treatments studied and used, but also in monitoring the health and well-being of the survivors as time went by. An expert from the National Cancer Institute was made adviser to the NWTSC to help in organizing long-term survivor information.

The National Wilms Tumor Study's multi-faceted, interdisciplinary structure became the model for subsequent pediatric clinical trials everywhere in the world.

The results of the far-sighted NWTSG planners are the hundreds of trail-blazing, informative articles published by the pioneering members of the original NWTSC and their successors. ■

SURVEY MONKEY

Many of you have already used Survey Monkey to email us important information and to complete forms such as our Annual Status Report. In addition to letting us know how you are doing, you can now update your change of address using Survey Monkey. Simply click on the link to Survey Monkey on our website, www.nwtsg.org. Using this link you can also complete a change of address form and we can download the completed form to update your records.

WHO CAN REPORT FOR ME

Why can't my mother/father/aunt report for me? If you are eighteen years or older anyone can report for you—as long as you give us written permission for them to do so. A Signature Authorization form is posted on our website under the Participants, Families and Friends page. If you would like someone else to report for you, please either print, complete and mail us this form, or ask us to mail it to you with a business reply envelope.

FACEBOOK

The NWTS now has a Facebook page. If you are a Facebook user, you can click the Facebook link at our website, www.nwtsg.org. There you will be taken to our National Wilms Tumor page and you can “like” our page as over 900 Facebook users have already done. Many participants are now using this site to ask questions and share stories about their experiences with Wilms Tumor and their lives after treatment was completed.