



New interactive database will fuel more extensive neuroblastoma studies

By Dr. Sue Cohn

The International Neuroblastoma Risk Group (INRG) task force, comprised of 52 neuroblastoma specialists and pediatric oncologists, recently finished collating clinical and biological information on more than 11,000 children with neuroblastoma from around the world. It was a watershed moment in the fight against this disease.

The database provides a unique resource for researchers focused on neuroblastoma. Never before have records from such a large cohort of patients been collected. Already investigators have conducted more than 20 neuroblastoma studies – many of them published in medical journals-- mining this information, leading to seminal revelations about prognostic factors, patterns of relapse, and the behavior of the disease in adolescents and young adults. The database has proven particularly valuable for analyzing rare subsets of patients, such as those whose cancer had metastasized to the lungs or brain.

Even so, the original infrastructure housing the database had limitations. Because the INRG demographic and clinical information could not be linked to tumor bank or genomic datasets, complex biologic studies were not possible. Now that is changing. INRG investigators have developed technologies for a Web-based Interactive INRG Database (iINRGdb) that will make linked data more accessible to researchers around the world.

This new infrastructure, housed at the University of Chicago, will allow more in-depth studies of neuroblastoma genomics, epidemiology, therapeutic strategies and long-term outcome, leading to more effective, personalized therapy for children with neuroblastoma and, ultimately, improved survival rates. Additionally, the database is being built in a way that will allow it to be extended to other cancers and diseases in the future.

The development of the iINRGdb would not have been possible without the generous support of the Children's Neuroblastoma Cancer Foundation (CNCF). Already, the iINRGdb has linked with the Children's Oncology Group biobank, and a unified Web site has been built where researchers can easily access the database.

Links to genomic databases in North America and Europe are expected to be established within the next year and data on more than 4,000 additional children with neuroblastoma will be uploaded in the next several months. The iINRGdb will facilitate updating information on these

patients continually, providing investigators with a truly invaluable resource for helping improve the outcome of children with neuroblastoma.