



FOR IMMEDIATE RELEASE

May is "NF Awareness Month"

Contact:

Allison Walsh, Communications Officer
(800) 323-7938, ext. 225 • awalsh@ctf.org
<http://www.ctf.org>

**Children's Tumor Disorder More Common Than Once Thought:
NF Strikes One In Every 3,000 Births**

_____ May, 2007 — While most parents don't know the early signs of neurofibromatosis (NF), and may never have even heard the term, the mere presence of six or more pigmented spots on their child's skin can be one early sign of the disorder's most common form, known as NF1. Called "cafe au lait spots," these patches appear slightly darker than a child's regular skin color and are just one of several possible signs that can help make the diagnosis. Early diagnosis is important because NF1 can cause tumors to form on nerves anywhere in the body, including the brain and spinal cord. May is "NF Awareness Month" and educating the public about the disorder will help lead to better detection.

The Clinical Care Advisory Board of the Children's Tumor Foundation has announced that recent research puts the incidence of NF1 at one in every 3,000 births, higher than earlier estimates. Although NF1 is an under-recognized disorder, it is more prevalent than the most common form of muscular dystrophy, cystic fibrosis, Tay Sachs, and Huntington's disease combined. A second form of NF, known as NF2, also was found to be more common than previously thought – occurring in one out of every 25,000 births. Half of all cases of NF are inherited from a parent who has the disorder, and the other half result from a "spontaneous genetic mutation" in families with no history of NF. NF affects people of all races and ethnic origins, and both sexes, equally. The new incidence figures don't reflect a rise in NF, but instead result from better studies.

The symptoms and severity of this progressive disorder vary greatly from person to person, with little predictability, resulting in a lifetime of uncertainty. NF1 can lead to loss of vision, bone and skeletal abnormalities, disfigurement, limb amputation, learning disabilities, cardiovascular defects, malignancy, and a variety of other complications. NF2 typically leads to hearing loss starting in late adolescence or young adulthood, followed eventually by total deafness. It also can cause cataracts and problems with balance and mobility. A third form of NF, called Schwannomatosis, can cause chronic and severe pain.

The Children's Tumor Foundation is the driving force behind NF research, a field that is advancing rapidly toward finding effective drug therapies for treating the disorder. Surgery is not always a viable solution in NF, as tumor removal sometimes poses the risk of damaging nerves and partial removal can result in regrowth, requiring repeated operations year after year.

"Thanks to progress in NF research, scientists are now poised to make discoveries that can dramatically affect the lives of children born with NF. By funding drug discovery initiatives and other pioneering research, we're working to end the devastating effects of NF," says Foundation President John Risner. "Clinical trials are underway to test the effectiveness of various drugs in treating NF. By helping to build a network of NF Clinics across the country, we're encouraging improved standards of healthcare for patients. And by raising public awareness of NF, the Foundation is helping to increase early diagnosis of the disorder which will promote better health management. With the public's help, we *can* find effective treatments and an eventual cure."

Comments from a local volunteer: _____

