

MEDIA ALERT * MEDIA ALERT *** MEDIA ALERT**

**Benchmark Survey on Primary Immune Deficiency Patients
Reveals Major Shift in Needs, Challenges**

Findings to be Presented at Immune Deficiency Foundation National Meeting

The results from the most-recent nationwide benchmark report on patients suffering from dangerous, rare primary immune deficiency diseases will be released at the 2003 Immune Deficiency Foundation National Conference June 20 in Baltimore. The report represents the best snapshot of the population currently available. No comprehensive population survey has ever been undertaken by the federal government to estimate the prevalence or the population characteristics of primary immune deficiency diseases in the United States.

Primary immune deficiency diseases are disorders in which part of the body's immune system is missing or does not function properly. In contrast to secondary immune deficiency diseases in which the immune system is compromised by factors outside the immune system, the primary immune deficiency diseases are caused by intrinsic or genetic defects in the immune system.

The Immune Deficiency Foundation, a non-profit organization serving primary immune deficient patients and their families, conducted the in-depth patient survey to provide a comprehensive portrait of this population with rare diseases.

WHEN: **Friday, June 20, 2003, 7:00 a.m. – 8:30 a.m.**

WHERE: **Grand Ballroom Salon V-VI**
IDF National Conference: Bayer Breakfast Symposium
Marriott Waterfront Hotel (700 Aliceanna St.)
Baltimore, MD

WHO: **Erwin Gelfand, M.D.**—Chairman, Department of Pediatrics, Professor of Pediatrics and Immunology, National Jewish Medical and Research Center
Jonathan Goldsmith, M.D.—Vice President of Medical Affairs, Immune Deficiency Foundation
Panel of Experts
Debra Sedlak, CPNP—Duke University Medical Center
Jerry Siegel, R. Ph.—Ohio State University
Jerry Winkelstein, M.D.—Johns Hopkins University School of Medicine
Kathy Crews—Survey participant, mother of a son with a primary immune deficiency disease and an IDF Board Member

A full copy of the report will be available at www.primaryimmune.org.

**To arrange on-site or advance interviews, please contact
Katherine St. Claire at 703/780-9629 or Mona Miller at 202/518-6699**