Duke Visit Commentary From Doctor Rosemary Boustany: **Update after Trip to Duke Hospital (June 12, 1999):** 

We went to Duke University and were seen by Dr. Rose-Mary Boustany, a specialist with Batten's disease. Dr. Boustany confirmed to us that Nathan <u>did</u> in fact have Batten Disease. She did say that we had caught it earlier than anyone she has seen before and that Nathan appears to have a less severe case. But the prognosis is still the same. She said that with being less severe that she has seen children live until they are 14 or so.

She stated, since Batten disease is so rare, not much research is being done to find a treatment. Although, we were informed that genetic research is moving faster than ever on this disease but funding is always an issue with research. Some other parents of children with Batten disease are lobbying the government to subsidize research with pharmaceutical companies to find a treatment. The greater the awareness of the disease the more potential governmental and philanthropic funding for research.