

**KATHLEEN TURNER  
 BECOMES SPOKESPERSON  
 FOR NIPF**

Among the more exciting developments for NIPF in 1998 was the news that Kathleen Turner agreed to be the spokesperson for NIPF. To have one of the countries leading actresses, in movies and on the stage, selflessly devoting time and energy to this cause, with no financial compensation, is thrilling. Ms. Turner was one of the organizers of the highly successful benefit dinner that took place in New York City at Nick & Toni's Cafe. (Story on page 1). Not only was it largely due to the efforts of Ms. Turner that there were so many celebrities present, but she also very generously paid to see Rosie O'Donnell get doused with water. It is obvious that the large turn out by the media was largely due to her presence and those of the other performers. The benefits to the foundation are obvious. Having a prominent, recognized celebrity speak out about a

City in September 1998. The evening was not only profitable, a little bit zany, unpredictable and fun, but of equal importance, NIPF made many new friends and gained new supporters. The story appears on page 1.

I would also like to extend a heartfelt "thank you" to our many supporters who made donations to NIPF over the past year. Your hard-earned dollars, shillings, pounds, francs, etc. go to the support services that NIPF provides, and to all important research effort. As of this year, NIPF supports not only a researcher in France, but also a researcher in England. So, as you can see, your donations are as needed as they are important.

What the members of NIPF, Board of Trustees, Scientific Advisory Council, International IP Research Consortium have accomplished by working together for just four years is remarkable. I know that as we progress into in the twenty-first century we will reach our goals.

**LETTER FROM THE  
 EXECUTIVE DIRECTOR**

In each successive newsletter, I have tried to report on the progress made over the past year. I have long been concerned that I might not have something really newsworthy to write about. And yet, I'm always amazed and thrilled at the extraordinary progress NIPF makes. The membership continues to increase significantly. The number of countries, with IP families and concerned medical providers, that are stands at 17. One of the proudest achievements is creation of the International IP Research Consortium. The dedication, hard work and commitment that the members bring to the research is remarkable. Although the problem we are dealing with is extremely complex, I am positive that we are on the march toward a solution. An update on the latest research meeting is on Page 4. I would like to express my gratitude to all those who organized and participated in the fund-raiser at Nick & Toni's Cafe in New York

**CONTENTS**

**Page:**

1. Letter from the Executive Director
2. Celebrities Wait Tables for NIPF
2. Heather Weiss's letter
2. We're Not Fruit Flies
3. Glossary
4. Bibliography: Articles available in 11 Languages
4. Update of International IP Research Consortium
4. Disease of a Lifetime
5. Richard Alan Lewis M.D. M.S.
6. Need for Funding



Rosie O'Donnell and Amy Irving at benefit dinner (Iris Zimmerman)