



National Incontinentia Pigmenti Foundation

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LETTER FROM THE EXECUTIVE DIRECTOR

I am very pleased to present the first issue of the NIPF newsletter. In it I have attempted to cover a wide range of issues that I believe to be of interest and concern to its members. Regular features of the newsletter will be articles about legislation that deals with genetic issues, a profile of a member of the Scientific Advisory Council, results of fundraisers, human interest articles written by members, updates on the progress of those involved in research, etc. I would like to invite everyone to contribute to the next edition of this newsletter. Names and locations will be kept confidential if requested. Please send in questions of a medical nature, comments, anecdotes, or just your random thoughts. If you have any ideas for a column, or wish to write one, please send it to me. Presently I am planning to publish this newsletter 4 times a year, but if it appears that the membership would like additional issues, and has interesting ideas for them, I would be happy to publish more frequently.

The membership of NIPF currently numbers approximately 125 individuals, and consists of patients, families, medical professionals, etc. NIPF memberships in such organizations as the Alliance of Genetic Support Groups, and NORD, its home page on the internet, and referrals from medical professionals are the main reasons for the growing success of the organization. NIPF is now in contact not only with people who are within the borders of the United States, but also has contacts in South America, Canada, Europe, Australia, Scandinavia, and the Middle East. To reach the goal of being all inclusive within the IP community our reach must be extended far more than is the case at present. This will take publicity, referrals, and time, but most importantly the cooperation of a great many individuals. Considering that the organization was

THE FIRST INTERNATIONAL RESEARCH MEETING

Founded just one year ago, I am proud to report that a great deal of progress has already been made. I do however need help from everyone to achieve my goals. I especially need help with fund raising as I am now in the process of organizing the first international research meeting, the entire cost of which falls on the shoulders of the NIPF.

I look forward to hearing reactions to this newsletter, and I will be sure to print all "Letters to the Editor."

Susanne Bros Emmerich

On September 27-29, the first international research meeting will take place in New York City. The conference is being sponsored and organized by the National Incontinentia Pigmenti Foundation, and is being hosted by the Mount Sinai School of Medicine. Currently the participants will be comprised of members of the NIPF's Scientific Advisory Council, as well as geneticists from Sweden, France and England. It is hoped that this meeting will be the start of a collaborative effort by those who are, and have for some time, been actively engaged in research to isolate the IP gene. Success in this area is the first step toward detection in utero and the search for a cure.

This meeting is the realization of one of the goals for the NIPF.

URGENT NEED FOR FUNDING

Among the main concerns at present is funding. As mentioned in the above article, the funding for the research meeting falls squarely on the shoulders of the NIPF. It is necessary to appeal to the membership to assist in this effort by helping to fundraise.

Having a coffee hour, lunch party, or

SCIENTIFIC ADVISORY COUNCIL HOLDS FIRST MEETING

An ambitious agenda was outlined on October 24, 1995, when NIPF held the first meeting of its Scientific Advisory Council (SAC). Aside from the substantive issues discussed, the gathering marked the first opportunity many of the Council's members had to meet face to face. This gathering was held at the convention center in Minneapolis, MN during the day of registration for the American Society of Human Geneticists (ASHG) meeting.

The SAC consists of ten members, six of whom attended, as well as a geneticist from Sweden who recently began his own IP support group, a geneticist from Florence, Italy, with many IP patients, and Dr. David Nelson, of the Human Genome Project of the NIH.

Following introductions, Susanne Bros Emmerich spoke of the current state of fund-raising. The first official fundraiser was held in the summer of