ipif
Incontinentia Pigmenti International Foundation

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LETTER FROM THE EXECUTIVE DIRECTOR

What a spectacular year 2000 was for Incontinentia Pigmenti! It was a year in which we reached many important goals. The most outstanding was the successful identification of the gene called NEMO that causes IP. New developments are constantly occurring, but it will be some time before we can match this achievement.

When the foundation began in 1995, our goals were clear. However, we could never have imagined how rapidly we would accomplish such growth and success. I would like to repeat what I've said many times before: none of our goals could have been met without the help and dedication of our many supporters.

Each year when we send out the newsletters some are returned *addressee unknown*. Those who move often forget to send us a change of address, or forget to send us their new e-mail address. As developments in IP are occurring at a rapid pace, we do not want anyone to miss current information, please let us know if you plan to move.

Please remember that you can always log on to the web site for current information. The site has been translated into several languages and has been greatly expanded.

It must be kept in mind, however, that this is no time for complacency. Each time we resolve one issue, another one appears. We are still very far from our ultimate goal. We must recognize that the problems we address are complex, and that the road ahead is a long one. It is easy to congratulate ourselves on what we have so far attained, but many more years of difficult research lie ahead of us. As a very famous man once said, "we are at the end of the beginning."

CONTENTS

Page:

NIPF CHANGES NAME TO IPIF

The **National Incontinentia Pigmenti Foundation (NIPF)** has changed its name to **Incontinentia Pigmenti International Foundation (IPIF)**. In 1995 when **NIPF** was founded the word *National* was incorporated into the title. At the time it was thought that if **NIPF** were able to contact families, medical providers etc. all over the United States we would consider **NIPF** as wholly successful. However, after six years, it has become obvious that we did not realize our community would encompass literally the entire world, and certainly not in the space of only a few years. To brag a bit, our success has been overwhelming.

The international nature of the **IPIF** is obvious. The International IP Research Consortium consisted of five laboratories, 4 of them in Europe, and for a brief time a sixth was in Scandinavia. **IPIF** maintains a database of several thousand patients, families and medical providers spread across almost every country in the world.

A number of changes have been made. A new logo has been designed. There is a new e-mail address: ipif@ipif.org, and please note that the web site address now ends with **IPIF.** New stationery has been printed as well as labels, envelopes and the brochure. All organizations, which currently list NIPF, have been notified. However, so as not to lose contact with anyone, we will maintain 2 telephone listings and will not drop the old e-mail address.

This is a big undertaking, but we felt a necessary one.

83% OF IP CASES HAVE SAME MUTATION IN NEMO GENE

Mutations in genes come in many different guises. They may be small changes in the thousands of units (bases) that make up the *NEMO* gene, or they may be larger alterations that cut out part or all of the gene. It was a big surprise to the IP consortium to find that many IP women (83%) carry an identical change in the *NEMO* gene, where over half of the gene is missing. This 'common' mutation is readily detectable with a laboratory test that can be performed on a small blood sample. So accurate diagnosis of IP is now possible in 83% of cases. Testing for this mutation has now been set up in several *(continued on page 2 col. 1)*

Swaroop Aradhya accepting the ASHG award. (See story page 2)