

# ◆ NEPIN Newsletter ◆

Volume 3, Issue 1

January 10, 2000

THE PURPOSE OF THE NEW ENGLAND PRIMARY IMMUNODEFICIENCY NETWORK IS THREEFOLD:

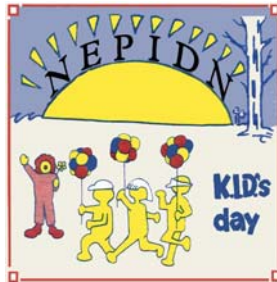
1: TO SUPPORT THE CLINICAL AND BASIC RESEARCH NEEDED TO BETTER UNDERSTAND AND TREAT PRIMARY IMMUNODEFICIENCIES (PI).

2: TO PROMOTE PUBLIC AWARENESS OF PRIMARY IMMUNODEFICIENCIES (PI).

3: TO PROVIDE MUTUAL SUPPORT AND ENCOURAGEMENT



## *Second Annual K.I.D's Day Was a Smashing Success!!*



Our second annual K.I.D.'s Day was held at Boston Children's Hospital on June 12, 1999. The weather was beautiful and the event was held



outdoors in the Prouty Garden. The day consisted of a carnival theme, with "Joe" the roving juggler, magician, and puppeteer, a face painting clown, and lively music by Okedoke Karaoke. The children also played games with a parachute, ran a sack race, and danced the limbo,



among other things. The food followed the carnival theme, with burgers, hot dogs, pizza, french fries, and ice cream. The cotton candy was a great hit, since its preparation was also



entertaining.

The event was sponsored by Baxter, Caremark, Centeon, Coram Healthcare, and Novartis Pharmaceuticals. Okedoke Karaoke donated part



of their time, as well. Approximately sixty people attended K.I.D.'s Day this year, which included some families from our first K.I.D.'s Day and some new families. Each family went home with tee shirts and a bag full of goodies, including a

*(Continued on page 2)*

## *Knights Sponsor Auction*

The Knights of Columbus Councils in Atkinson/Plaistow and Hampstead NH will hold an Auction to help fund research into Primary Immunodeficiency (PI) at 7:00 PM on April 1, 2000 at the Granite Rose Function Facility Rte 111, Hampstead, NH.

PI strikes at one million children with approximately one half of them going misdiagnosed or undiagnosed. All of the proceeds from this event will go towards funding research at Children's Hospital in Boston, MA. through NEPIN.

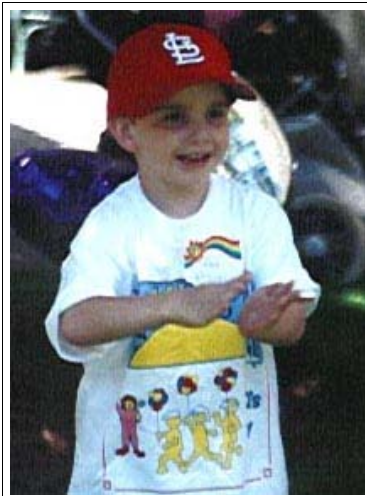
Tickets for the event will cost \$16.00 per person and will include a silent auction followed by a verbal auction. There will be mouth-watering hot and cold Hor D'oeuvres and a cash bar available throughout the evening. Tickets will be sold on a first come basis and can be ordered by calling Stan and Nancy Graziano at 603-362-5254.

We are currently asking businesses and individuals to donate or consign substantial items to auction. If you wish to donate an item or service, please call us!. Cash donations will also be accepted! Make checks payable to "P. I. Fund" at P.O. Box 692. Atkinson, NH 03811-0692.

(Continued from page 1)

book or sticker book for the next "I. V. day."

K.I.D.'s Day is an important event because it brings people together.



The day brings children with primary immune deficiencies together. They realize that they are not alone in receiving gammaglobulin. One child asked his mom, "Do you mean to tell me that all of these kids get I.V.'s? Wow!"

The day brings parents together so that they can share with one another about their similar situations. They



can make connections that continue long after K.I.D.'s Day. Mutual support is just a phone call or e-mail away!

The day brings healthcare professionals together with families. This year, Dr.



Raif Geha, Chief of Immunology, and Dr. Lynda Schneider, Director of Clinical Allergy and Immunology, both from Boston Children's Hospital attended the event. This gave families a great opportunity to get to know their doctors and to ask questions in a more relaxed and informal atmosphere. There were also representatives from Baxter and Caremark in attendance, so families were able to meet in person some of the people with whom they deal regularly by phone.

Much inspiration came from some very special people, Vicki and Fred Modell. They spent the day getting to know the families and other guests, and sharing words of encouragement with all of us. They helped to inspire many of us with their love of life, energy, caring, and hopefulness.

Mark your calendar! Our 2000 K.I.D.'s day is Saturday, June 3rd from 11 AM until 3 PM in the Prouty Garden of Boston Children's Hospital (Rain or Shine!) Join the fun! Since the event is funded by corporate sponsors, it is completely free to families who are dealing with a primary immune deficiency.



## ***IGIV Delivery -An Alternative Program.***

Have you had any problems obtaining IGIV therapy for a scheduled infusion? Are you concerned about the recent information regarding the IGIV shortage? If so, we have some good news to report to you.

In ongoing efforts to explore solutions to the IGIV constrained market Baxter Healthcare Corporation developed a program called the *IGIV Access Program*. This program provides a consistent supply of IGIV therapy directly to the patient. Baxter's goal is to assure IGIV therapy gets to the patients that need it most.

The advantages to the patient include:

- Service representatives to manage orders and answer questions
- Direct billing to your insurance carrier
- Pharmacy express-mail delivery to your preferred location
- Direct, toll-free access to a Baxter pharmacist
- Patient counseling and support services through the Immune Deficiency Foundation

To obtain more information about the *IGIV Access Program*, please contact 888-437-4262.

NEPIN would like to thank Baxter for funding the publication of this newsletter.

## ***Centeon Renamed***

Due to a merger between the pharmaceutical companies Rhone-Poulenc S.A. and Hoechst AG, IVIG manufacturer Centeon North America has been renamed Aventis Behring. Company spokespersons have assured us that this name change will have no effect upon the company's manufacture of IVIG.

## ***NEPIN Name Changed***

As you can see from our new masthead, we are now known as "NEPIN", the New England Primary Immunodeficiency Network. This change from "NEPIDN" will align our organization with the PI awareness campaign, as well as improve our acronym as we enter into our 3rd year!



## ***Primary Immunodeficiency (PI) Awareness and Education Campaign To Be Launched.***

One problem that many families with a PI (primary immunodeficiency) must deal with is explaining the disease to others. PI is not a commonly known term, such as MS or CF. Hopefully this situation will soon be improved.

In a unique collaboration coordinating the efforts of government and industry, the Jeffrey Modell Foundation has launched a two-year national campaign to help increase detection and management of primary immunodeficiency (PI) disorders. The campaign mission is to "educate physicians, health professionals, parents, and the general public concerning early diagnosis and effective treatment of primary immunodeficiencies.", according to the Congressional Appropriations Labor HHS Sub-committee report.

Teaming up with The Jeffrey Modell Foundation (JMF) for this campaign are:

- Four branches of the National Institutes of Health (NIH) including:
  - National Institute of Allergy and Infectious Disease (NIAID)
  - National Institute of Child Health and Human Development (NICHD)
  - National Human Genome Research Institute (NHGRI)
  - National Cancer Institute (NCI)
- The Centers for Disease Control and Prevention (CDC)
- The United States Surgeon General
- Pharmaceutical Industry Support

According to Anthony S. Fauci, M.D., Director NIAID, "Primary immunodeficiency has often been considered rare, even by skilled physicians. But the fact is that there are more than 70 forms of this condition and it affects approximately 500,000 individuals in the U. S., mostly children, who suffer with serious, recurring, and often life threatening infections."

There are an estimated additional 500,000 people who are either misdiagnosed or under diagnosed when it comes to explaining their recurring illnesses.

"In launching the public awareness campaign, our first mandate will be to educate health care providers and parents about the warning signs of the disease," said Duane Alexander, M.D., Director of NICHD. It is hoped that this campaign will make PI (primary immunodeficiency) a familiar household word and make it easier for those with the disease to be diagnosed.

We are enthusiastic and excited about this two-year campaign and invite all of you to join in with your suggestions and participation! Plans are to kick off the campaign in Spring 2000.

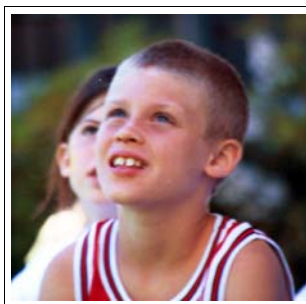
*Save the date for  
the third annual  
NEPIN K.I.D.'s  
Day June 3rd,*

New England Primary  
Immunodeficiency  
Network.  
P.O. Box 692  
Atkinson, NH 03811-  
0692

[http://www.tiac.net/  
users/jcfc/nepin](http://www.tiac.net/users/jcfc/nepin)

**In This Issue...**

- \* Second Annual K.I.D.'s Day was great!!!
- \* First Annual Auction being planned.
- \* IVIG Industry News
- \* National Public Awareness and Education Campaign



## *IVIG Recall Notifications*

Have you had the heart-stopping experience of finding out that the IVIG that was just infused into your child has been recalled? The International Plasma Producers Industry Association (IPPIA) will now be keeping a database of IVIG users, and will call the user directly in the event of a recall. Hopefully this will speed up the recall process so the users will find out BEFORE the product is used! If you would like to be added to this database, you can

request enrollment materials from IVIG manufacturers, the IPPIA, or the Immune Deficiency Foundation (IDF). Enrollment is also available through the toll-free telephone number at 1-888-873-2838 (1-888-

