

◆ NEPIDN Newsletter ◆

Volume 2, Issue 1

April 4, 1999

THE PURPOSE OF THE NEW ENGLAND PRIMARY IMMUNE DEFICIENCY IS THREEFOLD:

1: TO SUPPORT THE CLINICAL AND BASIC RESEARCH NEEDED TO BETTER UNDERSTAND AND TREAT PRIMARY IMMUNE DEFICIENCIES.

2: TO PROMOTE PUBLIC AWARENESS OF PRIMARY IMMUNE DEFICIENCIES.

3: TO PROVIDE MUTUAL SUPPORT AND ENCOURAGEMENT TO EACH OTHER.

Second Annual K.I.D's Day!!

Mark your calendar! Our 1999 K.I.D's day is Saturday, June 12th from 11 AM until 3 PM in the Prouty Garden of Boston Children's Hospital (Rain or Shine!) Join the fun! The more the merrier. Since the event is funded by corporate sponsors, it is completely free to families who are dealing with a primary immune deficiency.

NEPIDN's first K.I.D's day, held last June, was a tremendous success. It was sponsored by Baxter, Caremark, Centeon, Coram Healthcare, Friendly's and Okedoke Karaoke. Despite torrential rain and flooding, which drove the event indoors, about sixty people attended and enjoyed great food, games, music, karaoke, face-painting, and fellowship,

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Our singers were great!



The Games were fun!



Limbo !!



Where do we go from here??

As you see from the sidebar, this organization is all about the needs of people with primary immune deficiencies. It is currently a very loose network of people trying to encourage each other as we support the researchers who are working to solve our medical problems. Our first K.I.D.'s day was a great success, and it was wonderful to see some of you there last year. We hope that more of you will be able to make it this year. For our first year, NEPIDN has done very well, but we believe that it can be much more. As we begin our second year of existence, we need to find other ways to serve each other. We would like to fund research, but that will require some major fund-raising projects. We would like to hold a golf tournament, and we are looking for volunteers to help organize it. If you would be willing to help, please call Stan Graziano at 603-362-





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[http://www.tiac.net/
users/jcfco/nepidn](http://www.tiac.net/users/jcfco/nepidn)

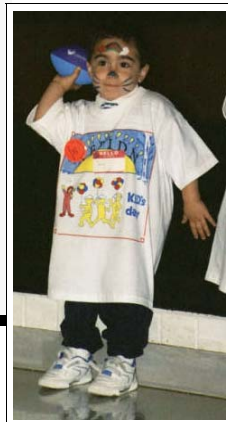
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Second Annual New England Primary Immune Deficiency Network K.I.D.'s Day!!!

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as you can see by these photos! Hopefully the weather will treat us better this year. Please let us know if you will join us! RSVP to Stan or Nancy Graziano at 603-362-5254 or the address above by June 2nd.

“Please let us know if you are coming to the second annual NEPIDN K.I.D.’s Day June 12th, 1999.”



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-UPDATE-U) and online

