

IDF ADVOCATE

THE NATIONAL NEWSLETTER OF THE IMMUNE DEFICIENCY FOUNDATION



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Third edition *Handbook* now available



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The flu vaccine: is it safe for you?



It's fall, and winter cannot be too far behind! Besides attending to things like furnace maintenance, you might also be wondering about whether or not there are special health recommendations or precautions that can help you get through the winter months in the best health possible. Influenza, known as "flu," is a serious infectious disease problem during the winter months. People with primary immune deficiency diseases may be at increased risk for the flu.

Public health authorities, including the Advisory Committee on Immunization Practices of the Centers for Disease and Prevention, regard influenza vaccination (flu shot) as the primary method for prevention of influenza and its severe complications. Individuals targeted for vaccination include those over 65 years of age or those with certain chronic medical conditions (such as primary immune deficiencies) and persons who live with or care for those at higher risk.

There are two types of influenza virus that cause human disease, Type A and Type B. Each year the types undergo changes, which make individuals susceptible to infection even though they may

have antibodies to other strains of influenza from prior vaccinations.

Influenza is spread by coughing and sneezing. After infection, there is an incubation period of one to four days. Infected individuals can infect others before symptoms begin and for about five days after symptoms begin. Symptoms include fever, cough, muscle aches, headache, sore throat, runny nose, and feeling run down. The cough and fatigue can last for a few weeks. Pneumonia and other complications can be very severe.

Inactivated vaccines recommended

The current recommendation for controlling influenza is the use of an inactivated (killed virus) vaccine. (While killed virus vaccines can be taken by individuals with primary immune deficiencies, live virus vaccines should *never* be taken as they can cause disease in people with weakened immune systems.) The flu vaccine should be given before the influenza season in October or November. This year's vaccine is trivalent, which means it contains three strains, two Type A and one Type B, grown in hens' eggs.

A MESSAGE FROM THE EDITOR

I hope you enjoyed the last issue of the *IDF Advocate*. We have received many positive comments about our new design and title. In this issue, *IDF* needs your help in cleaning up our database. Please take a moment to fill out the insert and send it back to *IDF*. Also, please send me your ideas for articles you wish to see in future newsletters. I want to make sure the *IDF Advocate* addresses the needs of our readers. Thanks for your input and support!



IDF ADVOCATE

EDITOR
Elizabeth Lee

MEDICAL EDITOR
Jonathan Goldsmith, M.D.

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The Editor
IDF Advocate
Immune Deficiency Foundation
40 West Chesapeake Avenue, Suite 308
Towson, Maryland 21204

Toll Free 800-296-4433
Direct 410-321-6647
Fax 410-321-9165
E-mail idf@primaryimmune.org
Web site www.primaryimmune.org

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THE FLU VACCINE, CONTINUED FROM PAGE 1

Little risk, possible benefits

People with primary immune deficiency diseases have trouble making antibodies and as a result have more serious or more frequent infections than other individuals. When vaccines are given, those with primary immune deficiencies may not respond by making enough or any antibodies. Even if you do not make antibodies, there is very little risk from a flu shot because the vaccine is a killed virus vaccine. The only risks are soreness at the injection site, and less often fever, tiredness, muscle aches, and headache. You will not get the flu from the shot! However, people allergic to eggs should not receive the vaccine, as there is a risk for more serious reactions.

Even if you do not develop antibody titers high enough to prevent influenza, you still might benefit from the shot by reducing your risk for hospitalization, pneumonia, and other complications. Therefore, many physicians will recommend influenza vaccination to you. The time to get the vaccination is in October and November of 2001, before the flu season gets into high gear. However, vaccination given later in the year may still be of some help.

Vaccines for household members

In addition to the person with a primary immune deficiency, those who live in the same household should strongly consider receiving a flu shot to reduce the chance that the virus will be brought into the home.

Remember that the flu season is getting close, so you need to see your doctor soon and make a decision about getting a flu shot!

Computer Associates helps IDF participants attend family retreat

Computer Associates International, Inc. recently donated \$10,000 to the *IDF* Southeast Family Retreat, which occurred on November 2-4, 2001 in Haines City, Florida. Once a year, over 200 patients and family members gather together to share a weekend of fun and fellowship, and participate in a number of informative educational programs. Costs are subsidized for the participants, due to the generosity of sponsors such as Computer Associates.

Topics covered at the retreat are designed to increase the knowledge of patients and their family members in the areas of ongoing research, treatment and cures, patient's rights, nutrition requirements, coping skills, and blood product health safety. A critical goal of the retreat is to help patients and families develop a sense of community and realize that they are not alone—they are part of a much larger family, the Immune Deficiency Foundation.

"It is through the generous support of our donors and sponsors, like Computer

BIOTERRORISM AND PRIMARY IMMUNE DEFICIENCY

IDF has received many inquiries about possible bioterrorism threats like Anthrax and Smallpox and the risks to individuals with primary immune deficiencies. These infectious diseases pose serious and real threats to all people, regardless of immune function. While infected saliva droplets can spread Smallpox (a virus) from one person to another, Anthrax (a bacterium) is extremely unlikely to be spread from person to person contact.

Anthrax can cause serious and fatal infections. Currently, individuals exposed to Anthrax are being treated with antibiotics, but preventive treatment is not recommended! Although a vac-

cine is produced in the US, it is only available to high risk military and lab personnel. IGIV does not offer any protection against Anthrax. Individuals with primary immune deficiency diseases should follow the same public health recommendations as the general population (see the CDC Web page at www.bt.cdc.gov).

Routine vaccination against Smallpox ended in 1972. If public health authorities determine that Smallpox vaccination programs are needed, people with primary immune deficiencies should not be vaccinated as certain forms of immune deficiency can predispose individuals to complications of vaccination.

For more information on the above, visit www.primaryimmune.org.

Year-end gifts

Each year, IDF asks its members to consider making a year-end gift. The proceeds from this appeal make a tremendous difference in funding our education and research programs. We hope that many of our friends—patients, families, medical professionals, providers of services and products, and others—will be able to participate by making a tax-deductible contribution this year.

You will soon be receiving information about a year-end gift in the mail. Or you

may make your gift today by sending a check to IDF, or calling to make a gift with Visa or MasterCard. For information on receiving additional tax benefits through a gift of appreciated securities, please contact Marcia Boyle at IDF.

Thank you for making such a difference in the lives of thousands of individuals affected by primary immune deficiency diseases.

Immune Deficiency Foundation
40 West Chesapeake Ave., Suite 308
Towson, MD 21204
Toll-Free 800-296-4433

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Rita Basso	John McGeary, Jr. <i>(a distribution from the John A. McGeary, Jr. Trust Fund)</i>
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Mark Austin	Thomas Ryan
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Top row, L to R: Sally Wyatt, Gail Moore
Bottom row, L to R: Brooke Wiley, Henry Wyatt, Kinsey Moore

COMPUTER ASSOCIATES, CONTINUED FROM PAGE 2

Associates, that IDF is able to help the hundreds of patients and families who attend the retreat each year," said Marcia Boyle, Founder of the Immune Deficiency Foundation. "IDF is truly grateful for the support and generosity of our sponsors and hopes to expand the Family Retreat Program into other areas throughout the United States, so we can provide peer support and educational opportunities to others affected by primary immune deficiency diseases."

Maitland, Florida resident Sally Wyatt, a Quality Assurance Engineer for Computer Associates, is the parent of a child with a primary immune deficiency. Each year Sally serves as a volunteer at the Southeastern Family Retreat. According to Sally, "It is a great opportunity to give back to the same community that has given us so much. It is also wonderful to work for a company that supports my cause."

Computer Associates presented the donation to the Immune Deficiency Foundation on September 21, 2001 in honor of Sally Wyatt's tremendous volunteer efforts.

2002 IDF Fellowship to support laboratory studies on gene therapy

The inability of a lymphocyte to kill a target cell is a central problem in primary immune deficiency diseases. That inability results from a flaw within a complex series of molecular events that are difficult to characterize. Even more challenging is the task of correcting the events so that the lymphocyte succeeds and the target cell is killed.

Because the possibility of doing so holds great promise, the Immune Deficiency Foundation supports the work of clinical scientists who are pursuing these challenges. One such scientist is Yatin M. Vyas, M.D., a pediatric hematology and oncology specialist and a research associate at the Sloan-Kettering Cancer Center. For his proposal entitled, "The Natural Killer Immune Synapse in Wiskott-Aldrich Syndrome," IDF has awarded him its 2002 IDF Fellowship of \$35,000.

"Natural Killer" (NK) cells play an important role in the immune system's attacks on target cells, and Dr. Vyas has succeeded in describing the interaction of healthy NK cells against target cells. His proposal is to study the interaction of unhealthy NK cells—such as those that

occur in patients with Wiskott-Aldrich Syndrome—against target cells. He hopes to understand how deficiencies in the NK cell's WAS gene reduce the NK cell's ability to kill target cells. Further, he hopes to discover how to inject a healthy WAS gene into the deficient NK cell and rectify the defect. (The use of a healthy gene to correct the function of an unhealthy cell is called gene therapy.)

"IDF's generous fellowship will help me take the next step in NK cell research," comments Dr. Vyas. "I believe that understanding the NK cell is critical to the future implementation of gene therapy in Wiskott-Aldrich Syndrome." For more information about the IDF Fellowship Program, please refer to the IDF website at www.primaryimmune.org.



Yatin M. Vyas, M.D.

IDF ADVOCATE

New and updated, the *IDF Handbook*

IDF is pleased to announce the third edition of the *Patient and Family Handbook for the Primary Immune Deficiency Diseases*. The new edition provides information on:

- The immune system
- 10 specific primary immune deficiency diseases
- Inheritance issues
- Specific medical therapy
- Issues that children and adults have about primary immune deficiency diseases.

To receive a free copy of this publication, please download it from our Web site at www.primaryimmune.org, or contact IDF at 800-296-4433.



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