

Primarily For You!

IDF National Conference Convenes in Baltimore
With 1000 Registered to Attend

The inaugural IDF National Conference is quickly approaching. We are expecting nearly 1000 individuals affected by primary immune deficiency diseases, family members, and friends of IDF to gather in Baltimore on June 21-23, 2001. Conference attendees will have the opportunity to participate in the first-ever IDF Day on Capitol Hill, attend two full days of educational sessions, visit an informational

Exhibit Hall, and connect with others at two evening social events. The fun-filled Youth Program includes a tour of Port Discovery, the Kid-Powered Museum in Baltimore, and an afternoon at Oriole Park at Camden Yards, cheering on the Baltimore Orioles! The three-day conference will conclude on Saturday evening with a special banquet celebrating IDF's 20th Anniversary.

IDF would like to thank the following companies for their

generous sponsorship of the Conference:

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Aventis Behring
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For an updated conference agenda, please see insert. ■

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FEATURED THIS ISSUE

- **NATIONAL CONFERENCE AGENDA** From sessions to suppers, from exhibits to an extravaganza event at the National Aquarium, IDF does it all Primarily For You!
- **RESEARCH GRANTS PROGRAM** IDF awards three two-year grants totaling \$100,000 each
- **PATIENT NOTIFICATION** Prompt, consistent, and confidential program offers alerts on product recalls and withdrawals
- **LOCAL CHAPTER CONTACTS** IDF's network of dedicated volunteers provides support for those affected by primary immune deficiency diseases and their families



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IDF Awards High-Priority Research Grants

Jerry Winkelstein, MD, IDF Medical Advisory Committee Chairman, is pleased to announce that after careful review of a record number of research funding requests, three exceptional proposals have been awarded two-year grants totaling \$100,000 each. In November 2000, the Foundation received twenty outstanding research proposals requesting consideration for funding through IDF's FY2001/2002 Research Grants Program.

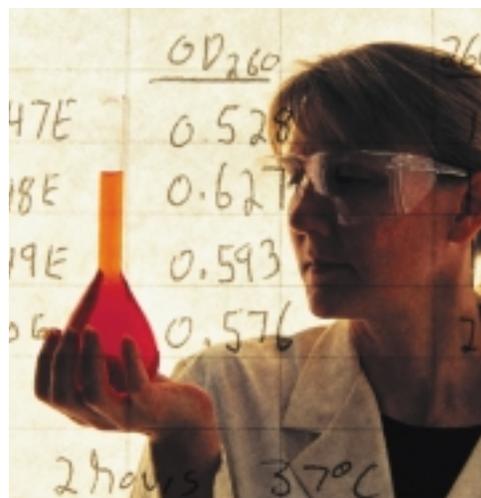
Applications were reviewed by the Medical Advisory Review Committee and approved by the Board of Directors. The current allocations to the following projects reflect the Foundation's wide-ranging and ever-increasing support of the specialty of primary immunodeficiency:

■ **Scott K. Durum, PhD**, National Cancer Institute, National Institute of Health, Laboratory of Molecular Immunoregulation, "*IL-& Receptor Signal Transduction*"

■ **Marianne T. Sweetser, MD, PhD**, University of Washington, Department of Pediatrics, "*CD-40 Signaling in Non-X-Linked Hyper IgM Syndrome*"

■ **Sarah L. Gaffen, PhD**, State University of New York at Buffalo, The Research Foundation, "*Molecular Signaling Pathways Used by γ Cytokine Receptors to Promote Lymphocyte Survival*"

IDF extends a gracious thank you to all applicants who submitted research proposals and we look forward to giving and receiving continued support from the medical and scientific community. ■



Dr. Barr Provides Public Testimony

IDF provided testimony before the House Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies on March 13, 2001. Dr. Richard Barr represented IDF, and requested continued congressional support for IDF projects related to primary immunodeficiency diseases. Dr. Barr also requested that Congress continue funding the plan to double the NIH budget by fiscal year 2003. A summary of the IDF testimony follows:

Since 1997, IDF has managed a registry funded by the National Institute for Allergy and Infectious

Diseases. The goal of the registry is to assemble a comprehensive clinical picture of eight primary immune deficiency diseases, and to develop estimates of prevalence, clinical course, and complications. These registries provide an invaluable resource for investigators conducting research on these diseases, and therefore IDF requested that Congress continue funding this program.

Because primary immunodeficient patients are the only population that requires life-long infusions of IGIV, IDF has been developing a national surveillance program to study the short and long-term effects of IGIV use. The establishment of a system to study this population is very

important because no prospective study on the health consequences of IGIV use has been performed, even though patients have received IGIV for over 20 years.

IDF fully supports the goal of doubling the NIH budget by fiscal year 2003. In recent years, NIAID sponsored research has shed new light on the genetics of the immune system and its relation to primary immunodeficiencies. Investigators are using this information to develop potential new therapies for primary immunodeficiencies, including gene-based therapies. This cutting-edge research has given patients hope that improved therapies, and eventually a cure, for these diseases may be on the horizon. ■



2001 Scholarship Campaign

The recent 2001 IDF Scholarship Campaign has been a major success. Since the word is getting out about the scholarships opportunities for individuals diagnosed with primary immunodeficiencies, the Foundation has received hundreds of inquiries nationwide from students seeking information about our scholarship. We were fortunate to receive 54 applications (29 from college freshman). Bill Wiser, a 2001 IDF Scholarship recipient, commented that *“This charitable award will help to broaden my work skills so that one day I can rejoin the workforce in a much healthier and happier capacity.”* IDF is very proud of the efforts of the Scholarship recipients and wishes them well in their future endeavors.

IDF SCHOLARSHIP WINNERS:

Name	College/University
Erin Balcom	Old Dominion University
James Barnes	Wayne State College
Michael Bergquist	Arizona State University
Matthew Bicknell	Cedarville University
Jodi Brink	Cambria Rowe Business College
Ashley Bryner	Salisbury State University
Michael Cahill	Akron University
Kristin Campbell	University of New Hampshire
Rachelle Cernuto	Marshall University
Jacob Duritsky	Cleveland State University
Erica Echols	Winthrop University
Marni Ferralli	California State University
Christopher B. Foisey	Florida Institute of Technology
Sharon B. Ford	Eastern Oregon University
Ira Lee Gant	University of North Carolina
Tiffany Giaccone	East Carolina University
Michael Giovanni	Pace University
John Guntkowski	Brevard Community College
Melissa Hammes	University of Iowa
Matthew LaPine	Rider University
Renae Lengen	Niagara County Community College
Kendra Luc	Southeastern Louisiana University
Cameron Miller	California State University
Bruno Nasimento	Valencia Community College
Michelle Riordan	LaSalle University
Brandi Ross	Western Carolina University
Alec Sabina	Southern Maine Technical College
Grant Tressler, II	Indiana University of Pennsylvania
William Wiser	Strayer University
Robert Witt, II	Pittsburgh Technical Institute
Joshua Wulff	Loyola University

ERIC C. MARDER SCHOLARSHIP FUND RECIPIENTS:

Carrie Almond	Concordia University
Steven Johnson	University of Oregon

Patient Notification System

IDF encourages all individuals who use or prescribe IGIV to enroll in the patient notification system, which was developed in response to the need for a prompt, consistent, and confidential method of alerting patients and health care providers in the event of IGIV recalls and withdrawals. You can enroll as a patient, parent, health care provider, or other. For more information on the notification system or to enroll, please call (888) 873-2838 or enroll online at www.patientnotificationsystem.org.

Features of the patient notification system include:

- **Right to information** - Patients are notified in the event there is a recall or withdrawal of IGIV.
- **Patient confidentiality is guaranteed** - A third party (National Notification Center) administers the patient notification system and will not release your name for any reason.
- **Industry wide** - All manufacturers, brands, and plasma derivative products are represented in the patient notification system.
- **Direct and active notification** - You indicate the method used to notify you.
- **Designed by plasma users** - IDF, Alpha One Foundation, National Hemophilia Foundation, and the Committee of Ten Thousand worked cooperatively to design this program.

Enrollment in the patient notification system is voluntary. However, the success of the system depends on you. IDF encourages you to enroll today.

Visiting Professor Program

The LeBien Visiting Professor has again been busy for the first quarter of 2001. Four medical institutions were visited by three LeBien Visiting Professors during this quarter:

- **January 11, 2001** - Northeastern Ohio University, Canton, OH - Jerry Winkelstein, MD
- **February 2, 2001** - University of Kentucky, Lexington, KY - Jerry Winkelstein, MD
- **March 2, 2001** - University of Nevada, Las Vegas, NV - Dick Hong, MD
- **April 3, 2001** - Hershey Medical Center, Hershey, PA - ME Conley, MD

The awarded institutions each scheduled combined Grand Rounds to include other departments including Pediatrics, Internal Medicine and Infectious Disease. Letters of appreciation have been received from several of the Hosts of Residency Training Programs acknowledging the invaluable experience that we are offering to the medical community through this program. The overall physician response is that IDF should be commended for its approach to educating both the public and physicians to improve their diagnostic acumen.

New Staff at IDF National Office

Melissa Patterson, MS, joined the IDF staff on March 1, 2001 as the Patient Advocate Manager in the Division of Patient Services. She will be assuming the role of direct patient casework by responding to the inquiries from patients and family members who call or email the IDF office with questions related to various aspects of primary immune deficiencies, including general information about diagnosis and disease management, access to health care and appropriate treatment, health insurance assistance and reimbursement, and life cycle issues such as education and employment. Melissa will also be developing and implementing need-based programs such as a health insurance/financial assistance program.

Melissa has a Master of Science degree in Genetic Counseling and is certified by the American Board of Genetic Counseling. For the past five years, she has worked as a Genetic Counselor at Johns Hopkins Hospital and Swedish Medical Center in Seattle, where she gained tremendous experience providing direct casework for individuals affected by numerous genetic diseases, including primary immune deficiencies. Please direct any questions related to the above topics to Melissa by e-mail at mp@primaryimmune.org or by telephone at (800) 296-4433. We extend a warm welcome to Melissa and are very happy to have her on board at IDF!

CHAPTER/PATIENT CONTACT NETWORK

Call the Immune Deficiency Foundation's Hotline at (800) 296-4433 and we will put you in direct contact with these local volunteers:

Arizona	<i>Tucson Phoenix</i>	Sonia Vohnout Bill Kahn
California	<i>Scotts Valley Huntington Beach</i>	Bonnie Doak Norman Abshear
Colorado	<i>Broomfield</i>	Joanie Sargent
Connecticut	<i>West Haven</i>	Evelyn Maselli Terri Lowell
Florida	<i>Port St. Lucie Bartow</i>	Lynne Szott Gail Moore
Illinois	<i>Aurora</i>	Lisa Verachtert
Indiana	<i>Indianapolis</i>	Rita Meldrum
Iowa	<i>Oxford Fairfax</i>	Cyndi Hora Jacqueline Langley
Kansas	<i>Olathe</i>	Sarah Anderson
Louisiana	<i>Shreveport</i>	Gail Nelson
Massachusetts	<i>Reading</i>	Barbara Mead
Michigan	<i>Pontiac</i>	Debbie Arnold
Minnesota	<i>Isanti</i>	Katherine Antilla
Nebraska	<i>Omaha</i>	Donna & Jerry Hobson
Nevada	<i>Las Vegas</i>	Ed Huyke
New Mexico	<i>Rio Rancho</i>	Janet Dokouzian
Ohio	<i>Solon</i>	Judy Ranallo
Oklahoma	<i>Sperry</i>	Tamie Bushyhead
Pennsylvania	<i>Newtown</i>	Terry Halper
Texas	<i>Austin Lubbock Plano Woodlands</i>	Mike Nunke John Robison Nancy Sherrard Kathy Crews
Washington	<i>Kent</i>	Kris McFalls
West Virginia	<i>Morgantown</i>	Lisa Ray

Change of Address Requested

IDF SUSTAINING CONTRIBUTORS

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American Red Cross
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(800) 296-4433 ■ FAX (410) 321-9165
www.primaryimmune.org



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IDF NATIONAL CONFERENCE AGENDA

Please note: Conference attendees will be notified of event locations and any changes in the agenda during registration.

DATES

Thursday, June 21- Saturday, June 23, 2001

LOCATIONS

Marriott Waterfront Hotel - Conference Headquarters Hotel (410-385-3000)
Courtyard by Marriott (443-923-4000)
Renaissance Harborplace Hotel (410-547-1200)

REGISTRATION

Conference registration will take place at the Marriott Waterfront Hotel, starting at 10 am on Thursday, June 21, 2001. Registration will be on the third floor (Grand Ballroom level) of the Marriott. From the reception area/check-in, take the elevator up one level to the Grand Ballroom level, or take the elevators to the third floor.

ANNOUNCING TWO NEW BREAKFAST SYMPOSIA

Friday, June 22, 2001 7:00 am - 8:30 am

IGIV 101: How Does Blood Become IGIV?

This session will educate listeners about the steps involved in the production of IGIV, with emphasis placed on blood and plasma donor selection, and viral testing and inactivation during the manufacturing process. The symposium will also provide an overview of the availability of IGIV and factors that affect supply.

Saturday, June 23, 2001 7:00 am - 8:30 am

Alternative Methods of Infusion of Gamma Globulin Therapy

This symposium will inform conference attendees on alternative methods of delivery of gamma globulin. In particular, the panel of speakers will address the safety, efficacy, and utility of subcutaneous administration of gamma globulin and self-administration of intravenous gamma globulin. Additionally, individual patients using both methods will discuss the treatment methods from their personal perspective.

PLAN ON VISITING THE FOLLOWING BOOTHS IN THE EXHIBIT HALL:

Alpha Therapeutic Corporation
American Red Cross
Angel Flight Network
Aventis Behring
Baxter Healthcare Corporation
Bayer Corporation
Centers for Disease Control
FFF Enterprises, Inc
The Genetic Alliance
IgG America

National Institute of Allergy and Infectious Diseases
Patient Notification System - Plasma Protein Trade Association
Patient Services, Incorporated (PSI)
ZLB Bioplasma Inc.

Thursday, June 21, 2001

10 am - 10 pm **Registration/Information Desk Open**
10 am - 5:00 pm **IDF Day on Capitol Hill**
7 pm - 9 pm **Dessert Reception**

Friday, June 22, 2001

7 am - 10 pm **Registration/Information Desk Open**
7 am - 8:30 am **Breakfast Symposium - IGIV**
7:30 am - 8:45 am **Continental Breakfast served in Exhibit Hall**
9 am - 10:30 am **Opening Session and Keynote Speaker**
10:45 - 11:45 am **Scientific Keynote**
12 pm - 1 pm **Box Lunches served in Exhibit Hall**
1 pm - 2:50 pm **Scientific Sessions:**

IGIV Therapy
Genetic Testing
Bone Marrow Transplantation
Gene Therapy

3:15 pm - 5:00 pm **Specific Diagnosis Sessions:**
Common Variable Immune Deficiency/IgG Subclass Deficiency
Severe Combined Immune Deficiency
X-Linked Agammaglobulinemia
Chronic Granulomatous Disease
Selective IgA Deficiency
Wiskott Aldrich Syndrome
DiGeorge Syndrome

6 pm - 10 pm **IDF Extravaganza at the National Aquarium in Baltimore**

Saturday, June 23

7:00 am - 5:00 pm **Registration and Information Desk Open**
7:00 am - 8:30 am **Breakfast Symposium - Alternative Methods of Administration of Gamma Globulin Therapy**
Continental Breakfast Served in Exhibit Hall
General Session
Concurrent Life Management Sessions
Box Lunches Served in Exhibit Hall
Concurrent Life Management Sessions
IDF 20th Anniversary Celebration Banquet
Pizza Party for Youth Program Participants

Friday, June 22, 2001

7:30 am - 6 pm **Day Care Program**
9 am - 11:30 **Youth Program - Ice Breakers and Educational Sessions**
12 pm - 5 pm **Youth Program - Port Discovery Kid-Powered Museum**

Saturday, June 23, 2001

7:30 am - 10:00 pm **Day Care Program**
9:00 am - 11:30 am **Youth Program - Educational Sessions**
12 pm - 5:00 pm **Youth Program - Orioles Game**

EXHIBIT HALL HOURS

Friday, June 22, 2001

7:30 am - 9 am
12 pm - 5:30 pm

Saturday, June 23, 2001

7:30 am - 9 am
12 pm - 5:00 pm

QUESTIONS?

If you are registered to attend the conference and have questions in reference to your registration or hotel accommodations, please call the IDF Meeting Manager at (414) 276-6445. All other questions should be directed to IDF at (800) 296-4433. We look forward to seeing you in Baltimore!