

IDF Annual Awards Dinner

The Immune Deficiency Foundation held its Annual Awards Dinner on May 12 in Seattle, Washington. At the dinner, IDF presented R. Michael Blaese, M.D. with the IDF Scientific Achievement Award for his ongoing work in gene therapy. Over ten years ago, Dr. Blaese performed the first gene therapy attempted on human patients. Dr. Blaese treated two young children, Ashi and Cindy, with Severe Combined Immunodeficiency (SCID). Both of them are doing very well today. Much was learned from these early gene therapy studies, which contributed greatly to the advancement of gene therapy to where it is today. The Scientific Achievement Award recipient is selected by the

IDF Medical Advisory Committee, chaired by Jerry Winkelstein, M.D.

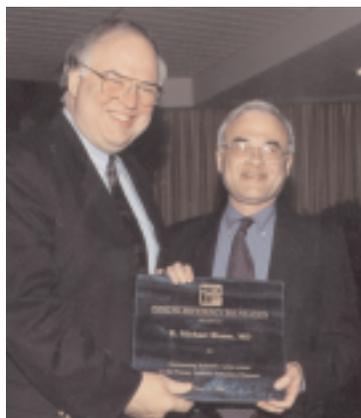
Also at the dinner, The IDF Florida Chapter was honored for their Florida Family Retreat as an Outstanding Local Program of the Immune Deficiency Foundation.

Aaron Ashcraft, IDF Board of Trustees member, presented the award to Gail Moore (West Coast) and Lynne Szott (East Coast). Last year, this program drew over 200 participants from the Florida area. Exciting programming, activities for all family members, and the strong support of the medical community led IDF to recognize the Florida Family Retreat as a model of excellence in local program services.

Other presentations at the IDF Annual Award Dinner included:

■ **Recognition Award - U.S. Food and Drug Administration, Center for Biologics Evaluation and Research (CBER).** IDF honored CBER for its commitment to the safety and well being of individuals affected with primary immune deficiency diseases by protecting and enhancing public health through the regulation of biological products.

■ **Novartis Fellowship - Dr. Chao Liu, Indiana University.** This is a com-



Dr. Michael Blaese (Left) received an award for Outstanding Scientific Achievement from Dr. Jerry Winkelstein (Right), Chair of the IDF Medical Advisory Committee.

petitive award based on the merit of the post-doctoral research in primary immune deficiency diseases.

■ **Safety Net Participants -** Alpha Therapeutic Corporation, American Red Cross, Aventis Behring, Baxter Healthcare Corporation, Bayer Corporation, FFF Enterprises. These corporate honorees were recognized for outstanding support to individuals and families affected by primary immune deficiency diseases by supporting the IGIV Safety Net Program.

■ **Recognition Award -** Presented to Miriam O'Day for her dedicated work as Vice President of Public Policy of the Immune Deficiency Foundation. Ms. O'Day has retired from IDF to pursue other career opportunities. She will be missed by the Foundation, but her accomplishments will be remembered. ■



Lynne Szott, Florida, East Coast (Left) Aaron Ashcraft, IDF Board of Trustees member (Center) Gail Moore, Florida, West Coast (Right) The Florida Chapter leaders received the IDF award for Outstanding Local Program.

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FEATURED THIS ISSUE

■ LETTER TO THE EDITOR

Board of Directors member and mother of David, the "boy in the bubble," Carol Ann Demaret writes in support of continued gene therapy advancements

■ NEW EDUCATION BROCHURE AVAILABLE

Sponsored by Baxter Healthcare Corporation, the new brochure helps patients keep an infusion log

■ NEW PATIENT NOTIFICATION SYSTEM

The new system provides a prompt, consistent, and confidential method for alerting patients and providers to IVIG recalls and withdrawals

■ LEBIEN RESEARCH GRANT AWARDED

Dr. Lloyd Mayer of Mount Sinai Medical Center in New York receives an IDF research grant of \$100,000 over 2 years

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This Newsletter has been sponsored by an educational grant from Bayer, Inc.

LETTER TO THE EDITOR - In Support of Continued Gene Therapy Advancements

We are on the cusp of medical breakthroughs so vast they can barely be imagined. Within the lives of our great-grandparents, people with diseases could be little more than comforted while nature took its course. Then some cures began to surface. Surgery

could help with some difficulties. Antibiotics were a Godsend. Then, with vaccines, came some few preventions. But here and now, on the eve of growing accomplishments in genetic manipulations, we can logically glimpse both cures and preventions for an ever-increasing range of human tribulations, whether from birth, or

acquired in the treacherous course of life. The promise for the very near future is not just to preserve some portion of precious life, but to enhance it at the core.

It has all come too late to save my beloved son, David, who was known as "The Bubble Boy". But I have been assured that what was learned from his Severe Combined

Immune Deficiency (SCID) has contributed toward the progress of genetic advances. As any parent can appreciate, the hope and excitement generated by these current scientific advancements is simply beyond description. ■

*Carol Ann Demaret
Member,
IDF Board of Directors*

New Education Brochure and Patient Notification System

IDF is pleased to announce our new education brochure "How to Keep an Infusion Log." The brochure was sponsored by Baxter Healthcare Corporation, and was created to assist patients in understanding the value and necessity of recording infusions and lot numbers.

To obtain a copy of the brochure, please call IDF at 1-800-296-4433 or order online at www.primaryimmune.org.

Baxter

In addition, a patient notification system has been developed in response to the need for a prompt, consistent, and confidential method to alert patients and health care providers in the event of IGIV recalls and

withdrawals. You can enroll as a physician, pharmacist, or patient.

Features of the patient notification system include:

- Right to information - Patients should be notified in the event there is a recall or withdrawal of IGIV.
- Guaranteed patient confidentiality - A third party (National Notification Center) administers the patient notification system and will not release your name for any reason.
- Industry wide participation - All manufacturers, brands, and plasma derivative products are represented in

the patient notification system.

- Direct and active notification - This system lets you determine the method best utilized to notify you.
- Program designed by plasma users - IDF, Alpha One Foundation, National Hemophilia Foundation, and the Committee of Ten Thousand worked cooperatively to develop this program.

Enrollment in the patient notification system is voluntary. However, the success of the system

How to keep an



Intra... ..

depends on you. The more patients enrolled in the notification system, the greater the obligation to maintain this voluntary system. IDF encourages you to enroll today.

To get more information on the notification system or to enroll please call 1-888-873-2838 or enroll online at www.notify1.com. ■

IDF Scholarships Winners Announced



IDF is pleased to announce the winners of the 2000 IDF/Novartis Pharmaceutical Scholarships. Undergraduate students from across the country with a primary immune deficiency disease were invited to apply for the scholarship opportunities. The IDF Scholarship Committee reviewed fifty-six applications, and twenty-eight scholarships ranging between \$500 and \$1500 were awarded. Additionally, six special scholarships were provided in the name of Eric C. Marder from his memorial fund. IDF is very proud of the efforts of the Scholarship recipients and wishes them well in their future endeavors.

Eric C. Marder Memorial Scholarship Winners:

Carrie Almond	Bishop, CA
Christopher Foisey	Chesapeake, VA
Ira Lee Grant	Jacksonville, NC
Morgan L. Gubler	Laverkin, UT
Jody Hodges	Pinckney, MI
Sara A. Shough	Mount Vernon, WA

IDF Novartis Pharmaceutical Scholarship Winners:

James E. Barnes	Omaha, NE
Sarah Barney	Marstons Mills, MA
Heather C. Braun	Bolingbrook, IL
Heidi L. Braun	Cherokee, IA
Ashley R. Bryner	Frankford, DE
Michael Cahill	Canton, OH
Michael Cattagio	Bethpage, NY
Rachelle Cernuto	Beckley, WV
Dora A. Cisneros	Houston, TX
Jessica Durose	Fridley, MN
Marni M. Ferralli	Simi Valley, CA
Sharon Ford	Clinton, MS
Stephanie M. Hanwell	Amesbury, MA
Leslie Harman	Reno, NV
Timothy Harper	N. Billerica, MA
Brian Hobbs	Williamstown, NJ
Christy Horton	Girard, PA
Amy Juneau	Bunkie, LA
Brian Juneau	Bunkie, LA
Heather Kaplan	Clinton, NJ
Rena Lengen	Lewiston, NY
Becky K. McGinness	Lake City, MI
Kevin Manning	Peoria, IL
Shane R. Oakland	Rock Lake, ND
Edward L. Penix	Hulbert, MI
Brad Roden	Indianola, WA
Jason Rollin	Waterford, MI
Amber Whited	Edinboro, PA

Operation Outreach Expands

IDF continues to develop new local programs and a network of patient contacts in regions of the country currently without an IDF program. On June 4, 2000, approximately seventy primary immune deficient patients, family members and friends boarded the River Belle paddle boat in Point Pleasant, NJ for an afternoon of learning and family fun. Dr. Jerry Winkelstein, Chairman of IDF's Medical Advisory Committee, provided the keynote lecture on primary immune deficiency diseases, and Dr. Donatella Graffino a clinical immunologist in Morristown, New Jersey led an interactive roundtable discussion with the meeting participants.

*We will be reporting on the
June 22, 2000 Operation Outreach
meeting held in St. Louis, Missouri.*



LeBien Research Grant Recipient Announced

IDF has awarded Dr. Lloyd Mayer of Mount Sinai Medical Center in New York a \$100,000 research grant over two years. Dr. Mayer's research is titled "Human Cytokine Knock-outs: A Model for Intestinal Disease in Patients with Common Variable Immunodeficiency."

Dr. Mayer is a Professor of Immunobiology, Medicine and Microbiology at Mt. Sinai Medical Center. He is also a recognized medical researcher and has received numerous honors from organizations such as Jaffe Food Allergy for Scientific Excellence, the Association of American Physicians, and the American Society for Clinical Investigations.

This grant is generously funded by Robert LeBien, Vice Chairman of the Immune Deficiency Foundation's Board of Trustees.

CHAPTER/PATIENT CONTACT NETWORK

Call the national Immune Deficiency Foundation Information and Referral Service at 1-800-296-4433 and we will put you in direct contact with these dedicated, local volunteers:

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