

## “Drive for the Cure” Raises Funds for Gene Therapy Research

The Washington State chapter of IDF held a successful charity golf tournament in June 2000. Held at the first-rate Sahalee Country Club in Redmond, Washington, Drive for the Cure netted \$33,000 and helped raise awareness of the important work of the Immune Deficiency Foundation. Proceeds from the tournament will help fund a national program sponsored by IDF: the Molecular Genetic Diagnostic Laboratory at the University of Washington. The lab provides free molecular diagnosis and carrier testing for primary immune deficiency diseases.

Drive for the Cure was arranged by a group of volunteers from the Washington State chapter of IDF and their friends. IDF would like to thank Kris McFalls, Lisa and Woody

Williams, and the rest of the committee for their hard work and dedication to running the tournament. Among the celebrities attending the 116 player tournament were Paul Westphal, Head Coach of the Seattle SuperSonics and Brad Owen, Lieutenant Governor of Washington. The Founding Sponsors of the tournament were Aventis Behring and FFF Enterprises. All holes and meals were sponsored, and Bayer Corporation provided tee prizes.

IDF is planning to expand its Golf Program by initiating additional charity tournaments around the country to generate funds and awareness for the Immune Deficiency Foundation. Look for upcoming articles in the IDF National Newsletter for dates and locations. ■

## 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:

<b>Arizona</b>	<i>Tucson Phoenix</i>	Sonia Vohnout Bill Kahn
<b>California</b>	<i>Los Gatos</i>	Bonnie Doak
<b>Colorado</b>	<i>Broomfield</i>	Joanie Sargent
<b>Florida</b>	<i>Port St. Lucie Bartow</i>	Lynne Szott Gail Moore
<b>Illinois</b>	<i>Flossmoor</i>	Darla Swanson-Byers
<b>Indiana</b>	<i>Indianapolis</i>	Rita Meldrum
<b>Iowa</b>	<i>Oxford Fairfax</i>	Cindy Hora Jacqueline Langley
<b>Louisiana</b>	<i>Shreveport</i>	Gail Nelson
<b>Massachusetts</b>	<i>Reading</i>	Barbara Mead
<b>Michigan</b>	<i>Pontiac</i>	Debbie Arnold
<b>Minnesota</b>	<i>Isanti</i>	Katherine Antilla
<b>Nebraska</b>	<i>Omaha</i>	Donna & Jerry Hobson
<b>Nevada</b>	<i>Las Vegas</i>	Ed Huyke
<b>New Mexico</b>	<i>Albuquerque</i>	Karen Fiato
<b>Ohio</b>	<i>Solon</i>	Judy Ranallo
<b>Oklahoma</b>	<i>Skiatook</i>	Tamie Bushyhead
<b>Pennsylvania</b>	<i>Newtown Indiana</i>	Terry Halper Judy Lunchuck
<b>Texas</b>	<i>Woodlands Lubbock</i>	Kathy Crews John Robison
<b>Washington</b>	<i>Kent</i>	Nancy Sherrard
<b>West Virginia</b>	<i>Morgantown</i>	Kris McFalls Lisa Ray

## IDF OFFERS SYMPOSIUM FOR PHARMACISTS AT ASHP CONFERENCE

IDF will be attending the Mid-Year Meeting of the American Society of Health-System Pharmacists (ASHP) December 3-7, 2000 in Las Vegas, Nevada. Pharmacists are welcome to visit the IDF booth in the exhibit hall as well as attend the IDF sponsored symposium on Tuesday, December 5 titled “Plasma Derivative: The Consumer Perspective in a Volatile Market.”

*For more information, please call Jennifer Bass at (800) 296-4433.*

Change of Address Requested

### IDF SUSTAINING CONTRIBUTORS

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## Announcing the Inaugural IDF National Conference

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**M**ark your calendars! The Immune Deficiency Foundation is pleased to announce its first-ever national conference in Baltimore, Maryland, June 21-23, 2001. The Marriott Waterfront Hotel at Baltimore's Inner Harbor has been selected as the site for this information and activity-packed three-day meeting - the first national meeting of significance and scope dedicated to bringing together individuals affected by primary immunodeficiency diseases. Platinum Sponsors of the first National Conference to date are Aventis Behring, Bayer, and FFF Enterprises.

At the conference, you will learn more about specific diagnoses, hear about scientific advances in treatment and therapies, learn about exciting innovations in disease management, interact with other individuals affected by primary immunodeficiencies,

and have a wonderful time. Expect to receive registration materials - including information about key speakers and an updated listing of sponsors - in early December. IDF is negotiating a discounted room rate at the Marriott, which will be listed in the registration materials. Transportation to the conference is on your own, but we intend to offer discounts on select air carriers.

All meals listed on the agenda are provided free-of-charge at the conference, including a Friday night party at the Baltimore National Aquarium and a Saturday night banquet at the Marriott. Day care will also be provided free-of-charge, along with a Friday and Saturday youth program with education sessions and fun activities for the children.

Plan to join us for IDF's First Annual National Conference as we prepare to celebrate our organization's 20th anniversary and give definition to our great expecta-

### CONFERENCE THEME CONTEST!

IDF invites everyone to submit ideas for a theme for the first National Conference. The contest winner will receive free individual or family registration along with free airfare! Fax or email your idea for a conference theme to Tracy Namie at (410) 321-9165 or [TN@primaryimmune.org](mailto:TN@primaryimmune.org). The deadline for submissions is January 1, 2001.

tations for the 21st century. We look forward to welcoming you and your family on June 21-23, 2001!

*A Preliminary Agenda appears on Page 3. For more information on the First Annual IDF National Conference, visit our web site at [www.primaryimmune.org](http://www.primaryimmune.org), or contact Elizabeth Lee or Jennifer Bass at (800) 296-4433. ■*

## FEATURED THIS ISSUE

- **PARTICIPANTS SOUGHT FOR IGIV CLINICAL TRIALS** Primaryimmune Services, Inc. launches clinical trials for OctaPharma and Grifols IGIV products
- **NURSING ADVISORY COMMITTEE INTRODUCED AT IDF** Aventis Behring provides an unrestricted educational grant to enable nurses to guide IDF in issues pertaining to nursing and patient care
- **IDF NOVARTIS FELLOWSHIP AWARDED** Dr. Carolyn Lutzko of Childrens Hospital Los Angeles receives a major grant for her research into the treatment of primary immunodeficiency diseases
- **IDF GOLF OUTING SUPPORTS GENE THERAPY RESEARCH** Sponsors, players and guests raise awareness and funds as they Drive for the Cure at Sahalee Country Club in Redmond, Washington



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

# Primary Immunodeficiency Diseases Registries Report on Progress

**W**e are pleased to report that IDF's National Institutes of Health sponsored registries are beginning to provide important information on primary immunodeficiency diseases. For one, the registry on Chronic Granulomatous Disease has gathered a great deal of important clinical infor-

mation, which has now been published. A comprehensive report, titled "Chronic Granulomatous Disease: Report on a National Registry of 368 Patients," by Winkelstein et al., appears in the May issue of the journal, *Medicine* on pages 155-169.

IDF manages eight NIH sponsored registries for U.S. residents with primary immunodeficiency

diseases. They include: Chronic Granulomatous Disease, Hyper IgM Syndrome, Leukocyte Adhesion Defect, Wiskott-Aldrich Syndrome, Common Variable Immune Deficiency, X-Linked Agammaglobulinemia, Severe Combined Immune Deficiency, and DiGeorge Anomaly. Patients are registered anonymously by their

physicians, and the patients may be living or deceased.

*If you are a patient, please share this information with your doctor. If you are a physician, and need information or forms, you may contact KK Marino, Director of Medical Registries at the Foundation's office at (800) 296-4433. ■*

## Clinical Trials for New IGIV Products Seek Participants

**T**he Immune Deficiency Foundation, through its subsidiary Primary-immune Services, Inc. (PSI), is conducting U.S. clinical trials for new IGIV products. Per the requirements of the U.S. Food and Drug Administration, a clinical trial must be performed with any IGIV product before it can be licensed for use in the United States.

IDF is currently conducting a clinical trial for Octapharma AG, a European producer of IGIV. The product is Octagam® Immune Globulin Intravenous (Human) 5% Liquid made with U.S. source plasma. This product has been sold in Europe and elsewhere for over eight years.

In February 2001, PSI will be conducting an IGIV clinical trial for Grifols SA, a plasma product manufacturer from Barcelona, Spain. Grifols has a state of the art facility in Barcelona and their product, Flebogamma® will be used during the trial. Flebogamma® is a 5% liquid product made with U.S. source plasma and is currently sold in over 20 countries.

Participants in either trial will receive free product for one year. In addition, the cost of their physician visits and lab tests will be paid for during the trial. Patients are given an initial physical examination, and receive IGIV infusions every 3-4 weeks at 300-600 mg/kg/infusion.

The following is documented information relevant to both



Octagam® and Flebogamma® IGIV:

- Contains mainly Immunoglobulin G (IgG) with a broad spectrum of antibodies against infectious agents
- Contains all the IgG activities which are present in the normal population.
- Prepared with U.S. source plasma from greater than 3500 donors.
- All plasma donation centers meet or exceed U.S. FDA criteria.
- Licensed throughout the world.

*To participate in the clinical trials or for more information, contact Dr. Paul J. Pinciaro, Director of Research of the Immune Deficiency Foundation at (800) 296-4433. ■*

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**GRIFOLS**

# IDF National Conference Preliminary Agenda

## June 21, 2001 Thursday

- 10 am - 10 pm Registration  
11 am - 5 pm Pre-conference activities include an IDF Day on Capitol Hill  
7 pm - 9 pm Dessert Reception

## June 22, 2001 Friday

- 7 am - 10 am Registration  
8 am - 9 am Continental Breakfast  
9 am - 5 pm Day Care and Youth Programs  
9 am - 12 pm Opening Ceremony  
IDF General Session and Keynote Speakers  
The Normal Immune System  
Primary Immune Deficiencies  
12 pm - 1 pm Lunch  
1 pm - 3 pm Scientific Sessions  
IGIV Therapy  
Genetic Testing  
Bone Marrow Transplantation  
Gene Therapy  
3 pm - 5 pm Specific Diagnosis Sessions - Disease overview, treatment, research advances, and Q&A  
Common Variable Immunodeficiency and IgG Subclass Deficiency  
Severe Combined Immunodeficiency  
X-Linked Agammaglobulinemia  
Chronic Granulomatous Disease  
Selective IgA Deficiency  
Wiskott-Aldrich Syndrome  
DiGeorge Anomaly  
6 pm - 10 pm IDF Extravaganza at the Baltimore National Aquarium

## June 23, 2001 Saturday

- 8 am - 9 am Continental Breakfast  
9 am - 5 pm Day Care and Youth Programs  
9 am - 12 pm Life Management Sessions  
Lifestyle - Managing your career, marriage, family, and friends  
Health - Nutrition and exercise  
Parenting - Education for yourself and your children  
12 pm - 1 pm Lunch  
1 pm - 5 pm Life Management Sessions  
Health Insurance and Reimbursement  
Schooling Issues - How to work with your child's school system  
New Health Legislation  
Blood Safety and Availability - Federal policy update  
7 pm - 10 pm IDF 20th Anniversary Celebration and Closing Ceremony

## IDF's New Nursing Advisory Committee

Nurses serve an integral role in providing health care for individuals with primary immune deficiency diseases. Coordinating care, providing patient education and counseling, administering IGIV infusions, and advocating on behalf of patients with third party payers are only a portion of the responsibilities of nurses specializing in the care of primary immune deficient patients. In recognition of the significant relationship that nurses have with patients, physicians, and other members of the health care teams, IDF is introducing a Nursing Advisory Committee.

Volunteers serving on the Nursing Advisory Committee will guide IDF in issues related to nursing and patient care. In addition, the Nursing Advisory Committee will provide direction for program development in the areas of IDF local activities and continuing educational opportunities for IGIV infusion nurses. A Steering Committee of eight nurse managers from major university medical centers across the country convened in October 2000 to develop specific components of the nursing program. Aventis Behring has generously provided IDF with an unrestricted educational grant to support the development of the Nursing Advisory Committee.

*Nurses interested in working with IDF on a local or regional basis may contact Jennifer Bass at IDF at (800) 296-4433.*

## NOVARTIS Fellowship

The 2000 IDF Novartis Fellowship grant of \$25,000 has been awarded to Dr. Carolyn Lutzko, a Post-doctoral Fellow in Immunology and Bone Marrow Transplantation at Childrens Hospital Los Angeles. Dr. Lutzko has been chosen as the recipient of this award for her contributions to the research and treatment of primary immunodeficiency disorders. Her study is focused on improving the mechanism by which gene therapy can be performed in patients with primary immunodeficiency diseases. This is the 17th annual IDF Novartis Fellowship that has been awarded.

Dr. Lutzko received her clinical training from the University of Toronto in Ontario, Canada, where she trained in the Laboratory Medicine and Pathobiology under the supervision of Ian Dube. In 1999, she joined Dr. Donald B. Kohn at Childrens Hospital Los Angeles, Division of Research Immunology and Bone Marrow Transplantation. Dr. Lutzko's studies have produced the first demonstration of what has emerged as a significant problem in gene therapy: the immunologic response to "normal" gene products in the setting of genetic deficiencies.

*The Immune Deficiency Foundation and Novartis are proud to recognize the accomplishments of Dr. Carolyn Lutzko, and commend her continued commitment and dedication to the better understanding of primary immunodeficiencies disorders.*