

IDF ADVOCATE

THE NATIONAL NEWSLETTER OF THE IMMUNE DEFICIENCY FOUNDATION



PI Awareness Week Activities

PAGE 1

Caregiving Strategies



PAGE 4



IDF Advocacy at Work for You

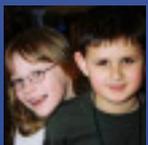
PAGE 8

Pick The Next Conference Theme

PAGE 9

Conference Theme Contest

Do you have a creative theme for the 2005 National Conference of Primary Immunodeficiency? The contest winner will receive free registration and housing for conference nights. Submit theme ideas by August 31, 2004 to [Phylic@idff.org](mailto:phylic@idff.org) or via mail to phylic@idff.org.



IDF Weekend Family Retreats Pennsylvania

PAGE 11

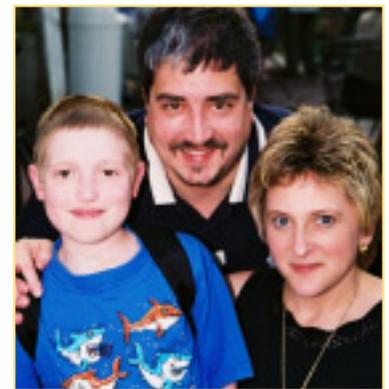


Bayer HealthCare
Biological Products Division

This Newsletter is sponsored by an educational grant from Bayer Healthcare



National Celebration Elevates Understanding and Awareness: IDF Launches First Fully Integrated Primary Immunodeficiency Awareness Week Campaign



National Primary Immunodeficiency Awareness Week occurs during the third week in April each year. In keeping with the mission of the Immune Deficiency Foundation (IDF), the organization leverages this designation to increase awareness among varied audiences nationwide. The fully integrated 2004 campaign included elements to promote education, advocacy and fund-raising efforts for research. IDF achieved its goal for the week – to conduct activities that increase the strength and reach of IDF and awareness of primary immune deficiency diseases. Specifically, IDF sought to reach new individual, health-care provider and legislative audiences. Additionally, IDF educated the general public about these rare disorders and invited the primary immune deficiency disease community and others to raise financial support for IDF programs and research.

IDF Convenes First-ever Consensus Meeting to Develop Clinical Care Guidelines to Improve Health Outcomes

Last year's landmark study by the Immune Deficiency Foundation found that people affected by primary immune deficiency diseases often go undetected and untreated, for many years. Meanwhile, many individuals affected by these rare disorders may suffer repeated serious infections and pneumonias that can lead to long-term irreversible health consequences. In response to the problem, the IDF, in its leadership role, convened for the first-time a consensus meeting of North America's foremost immunologists to address the lack of awareness about primary immune deficiency diseases, delayed diagnoses and inconsistent

continued on page 2

State and Federal Support of PIDD



IDF Local Volunteers Attend IDF Volunteer Leadership Conference in Raleigh, North Carolina



Awareness Week continued from page 1

treatment regimens.

The meeting, held April 15-16, 2004 in Raleigh, NC, produced a blueprint for developing clinical care guidelines with the goal to decrease the time for patients to get diagnosed and establish treatment and care guidelines for individuals with primary immune deficiency diseases. The guidelines and leadership meetings were sponsored by Bayer Healthcare Corporation.

“The clinical care guidelines that will be established will change the face of how those living with primary immune deficiency diseases are diagnosed and treated,” said Jonathan Goldsmith, M.D., interim president of IDF. “With today’s technological advances and access to information, a 9.2-year diagnosis period is not acceptable. It is our responsibility, as medical professionals, to determine what constitutes the best care, treatment, and methods of delivery to ensure access to equitable and quality care for patients and families.”

The goal of this two-day consensus meeting will be to deliver the IDF’s first comprehensive, evidence-based

diagnostic and clinical care guidelines for primary immune deficiency diseases for patients, caregivers and healthcare providers. The guidelines, which will be available later this year, will include recommendations, strategies, and additional information to help healthcare providers and patients make informed decisions about appropriate healthcare for those living with primary immune deficiency diseases. In addition, the guidelines will be disseminated to federal agencies, practitioners, insurance companies, and medical and patient associations and journals. The committee members include Rebecca H. Buckley, M.D., Chair, Mark Ballow, M.D., Francisco Bonilla, M.D., Ph.D., Erwin Gelfand, M.D., Richard Hong, M.D., Roger Kobayashi, M.D., Bruce Mazer, M.D. and Hans Ochs, M.D.

IDF Hosts Volunteer Leadership Conference

A National Volunteer Leadership Conference was held April 16–18, 2004, also in Raleigh, N.C. The conference brought together IDF volun-

continued on page 3

IDF ADVOCATE

VICE PRESIDENT, MARKETING AND COMMUNICATIONS
Candace Steele, M.B.A.

PUBLIC RELATIONS INTERNS
Kate Fremont-Smith
Kathleen O'Brien

PROGRAM COORDINATOR
Tracy Namie

MEDICAL EDITOR
Jonathan Goldsmith, M.D.

IDF Advocate is published quarterly by the Immune Deficiency Foundation. To obtain a free subscription, please contact:

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

Copyright © 2004 by the Immune Deficiency Foundation

The Immune Deficiency Foundation is a publicly supported tax-exempt organization as described under Section 501(C)(3) of the Internal Revenue Code of 1954, as amended.

teers, including primary immune deficiency diseases patients and family members, from 32 states for a week-end of training with the latest information, research, news, and outreach tools to continue raising awareness and improving the quality of life for individuals with these rare disorders. Kris McFalls, IDF volunteer, said, "What made this week even more remarkable was having the opportunity to connect with other volunteers. Meeting other people like me who are dedicated to improving the lives of those living with primary immune deficiency diseases was an empowering experience that made me a better advocate for those who are affected by these disorders."

IDF volunteers plan local meetings and serve as a resource for thousands of patients and families throughout the year.

Extending Reach to Medical Professionals

G. Richard Barr, M.D., Chairman of the IDF Board of Trustees and Jonathan Goldsmith, M.D., IDF, Vice President of Medical Affairs and Interim President, presented to the American College of Allergy, Asthma and Immunology (ACAAI) Board of Regents to discuss methods by which both organizations may collaborate in the future. Reflecting on the event, Dr. Barr said, "It's important for us to reach out to this group of 4,000 specialists. We look forward to working together in the future."

Advocacy at the Federal and State Level

As an important part of IDF's mission to advocate on behalf of individ-

uals affected by primary immune deficiency diseases and their families, IDF worked with volunteers throughout the U.S. to educate state and federal policymakers about primary immune deficiency diseases. These volunteers and IDF staff secured proclamations recognizing Primary Immune Deficiency Awareness Week from the following states: Maryland, Wisconsin, Connecticut, Louisiana, Tennessee, Minnesota, Texas, Virginia and West Virginia. Members of the U.S. Congress issued statements on the House and Senate Floors and/or sub-



Dr. Roger Kobayashi Addresses IDF Volunteers

mitted statements to the Congressional Record. The following made statements that were entered into the Congressional Record: Sen. Durbin, (D - IL), Sen. Landrieu (D - LA), Sen. Mikulski (D - MD), Sen. Murray (D - WA), Rep. Baldwin (D - WI), Rep. Boehlert, (R - NY), Rep. Brady (R - TX), Rep. Brown (D - OH), Rep. Jenkins (R - TN), Rep. McCrery (R - LA), Rep. Price (D - NC)

Retaining Plasma Donors through Education

Baxter Biolife and IDF collaborated to pilot a "Putting a Face on Primary

Immune Deficiency Diseases" campaign. This program, held at six Baxter plasma collection centers in the Pacific Northwest, brought plasma donors to the centers to participate in a "Food, Fun and Facts" event to educate them on the importance of

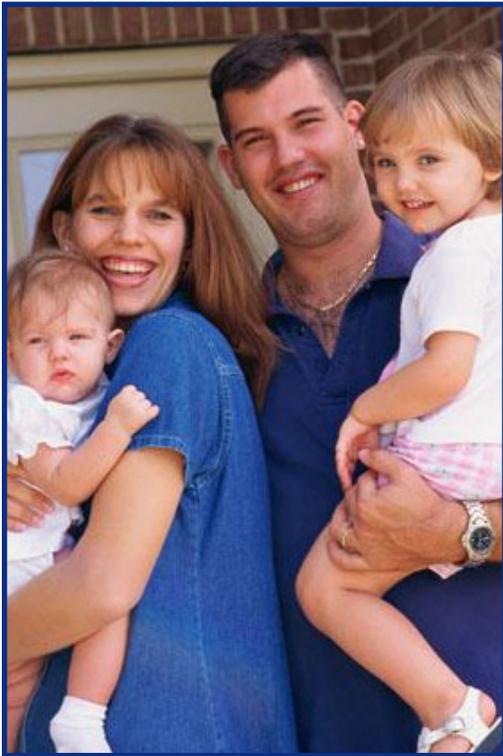


Terry Tenbrunsel, of Bayer Corporation, welcomed volunteers to Raleigh.

their plasma donation and how it helps improve the lives of patients with primary immune deficiency diseases. Plasma donors will continue to be invited to contribute their payment for their plasma directly to IDF and are encouraged to remain an active plasma donor. The proceeds helped to underwrite scholarships for families to attend the IDF Family Weekend Retreats. Amy Cynkar, Marketing & Corporate Communications Director for BioLife Plasma Services commented on the event, "We are pleased to work with IDF to bring these positive programs to our local communities, which in turn will assist families."

The activities planned and implemented during National Primary Immunodeficiency Awareness Week underscore the mission of IDF and lay the foundation for greater recognition of this community in coming years. ■

Strategies for Caregiving: Developing Coping Mechanisms through Self-Understanding



Kathy Antilla was very concerned about her son Isaac when he began to battle infection after infection shortly after his birth. No one could tell her why. When Isaac turned five, he was finally diagnosed with Common Variable Immune Deficiency (CVID), a rare and chronic immune deficiency disease, which would affect Isaac for the rest of his life. At first Kathy was thrilled that the doctors had a diagnosis, however she was terrified because she had no idea what this meant for Isaac's future.

Coping with a primary immune deficiency disease is difficult not only for the person with the illness, but also for the people who love and want to care for that person. It is not always easy to know how best to care for a loved one in a way that will make life enjoyable for the caregiver, the individual, and everyone else involved. An important idea to remember is that with adjustment and time, anybody; a spouse, parent, grandparent, or child, can learn how to become a successful caregiver.

Kathy, along with other caregivers, learned that it was normal to feel scared, overwhelmed, and helpless when Isaac was diagnosed with an immune deficiency. One of the best ways she learned to overcome these feelings was by becoming proactive in understanding the diagnosis and treatment. She began to research the disease in books, on the Internet, and by

making a list of questions to ask Isaac's experienced doctors. Kathy also began reading about the Immune Deficiency Foundation. There she found people educated in primary immune deficiency diseases who were able to talk to her about many of her concerns. Through research, caregivers can discover if there are alternative treatments or delivery methods for therapies. Caregivers can also find ways to make the individual feel more comfortable.

Gail Moore, a primary caregiver to her daughter, Kinsey, describes how she and her daughter had fun making art projects and cards for the nurses and doctors in the hospital. For Gail, developing a relationship with her doctors helped her recognize that she was capable of understanding the disease and that there were people who wanted to help. Developing a good relationship with the person's immunologist and with the nurses administering therapy helps caregivers and those for whom they are giving care feel more comfortable and better equipped to cope with the disease.

Keeping records and staying organized also helps a caregiver to maintain a sense of control. Caregivers often keep a file and update their medical records such as lab results, hospital summaries, and physician summaries. Kathy has kept an extensive binder with all letters, lab results, orthopedic records, and local and regional hospi-

tal information, since Isaac's birth. She says that it's really important for her to be organized because she can hold doctors and nurses accountable for their actions and can also provide doctors and nurses with pertinent, up-to-date medical information on her son's history when necessary.

If a patient is undergoing treatment, the best way to track recovery is to keep a log. For example, many caregivers keep an infusion log of the date and time of the last infusion. This log also includes lot numbers of the product, which can be helpful in the event of a product recall. Also, caregivers can manage their finances by tracking medical bills and insurance statements. Kathy hopes that her son will see the work she puts into his disease management and that one day he will learn to do the same for himself.

By staying organized, caregivers also develop good time management skills. Tools that assist in time management include taking charge, delegating, and prioritizing schedules. They think about what is most important to get done today, what can wait for tomorrow and they are not afraid to say "no." Successful caregivers remember not to sweat the "small stuff."

Maintaining a positive attitude is essential to becoming a good caregiver says Melissa Schweitzer, Director of Patient Advocacy at the Immune Deficiency Foundation. Melissa, who also is diagnosed with CVID, understands that caregivers should concentrate on what they can do instead of what they cannot and that they should appreciate their good days. However, sometimes they have to say to themselves, "My body doesn't always do what I want, but my brain is still working and I'm still able to love and together that helps me have the kind of life I enjoy." Developing a sense of humor and thinking of ways to bring laughter and fun into life is a great idea. Melissa also suggests planning something to look forward to after treatments. For example, going out to dinner or lunch after a doctor or infusion appointment can make managing the disease seem like less of a chore.

Overall, good caregivers must have realistic expectations and strength. When things get tough they need to accept that everyone experiences some sorrow or misfortune in life. Melissa's volunteer work at the Ronald McDonald home and a soup kitchen for the homeless helped her to appreciate how fortunate she is despite her illness. Melissa also advises to think positively about the disease by listing all the positive aspects of taking care of a chronic illness. For example, being a good caregiver gives one a better understanding for others experiencing similar situations or difficulties. It also helps one to build personal strength to help them cope with other difficult challenges that may arise in the future.

Emphasizing the normalities of life, rather than dwelling on the illness helps those individuals with a primary immune deficiency learn how to lead normal lives. Caregivers can encourage the person to go after their dreams and help them find ways to successfully achieve those goals. Gail Moore advises other primary caregivers to live for today. As a parent, Gail allows her daughter to lead as much of a normal life as possible. Today, Kinsey is an

“Flexibility and balance in one’s day-to-day life are key factors in resilience,” according to Reginald Nettles, Ph.D.

honor student at her local school and a competitive gymnast. She is also active in church activities, chorus, dance, soccer, and community service.

However, a caregiver also needs to acknowledge that at times, coping with a primary immune deficiency disease is overwhelming and difficult. Once in a while it is okay to give in to the emotions that go along with this and they should allow themselves to feel this way. Melissa described growing up with CVID and how hard it was for her to miss so much school because her classmates had difficulty under-

standing that she just wasn't feeling well. "I had to tell them that yes, I have this disease and I just can't always do everything they can," she said.

Also, caregivers should not be afraid of getting support from others who want to help or may be dealing with the same illness. Caregivers need to remember that they are not alone. Kathy says that even giving support can be helpful because talking to other people who are dealing with this disease helps her see how far she has



come. Caregivers need to give themselves credit for the challenges with which they cope.

Most importantly, caregivers allow some time to relax once in a while so they can re-energize. A caregiver

should not get too caught up in taking care of another person. At least once a day they should make plans to get out of the house and exercise, go out for lunch or coffee with a friend, or take a relaxing bath. Caregivers should realize that they must always take care of themselves in order to best care for their loved one.

Primary immune deficiencies are life-long chronic disorders, with unpredictable periods of more acute illness. As a result, caregivers may live with constant stress, punctuated by periods of major illness and disruption. At these times in particular, it can be very important to have learned skills that enable resilience, or the ability to bounce back from adversity. According to Reginald Nettles, Ph.D.,

founder of Psychological and Professional Coach Services in Columbia, MD, flexibility and balance in one's day-to-day life are key factors in resilience. Dr. Nettles says, "Close relationships with supportive

family members and friends, and the ability to experience and express strong emotions are essential. Although it is not healthy to dwell on sadness and grief, it is important to be able to face these feelings honestly when they occur." Joy can arise in life with a chronic illness, but usually not without facing the unhappy feelings when necessary. It should also be noted that professional help can be very beneficial when stress, anxiety and depression interfere with normal activities.

Each of the individuals mentioned in this article describes some of the ways they have managed their lives with PIDD or as caregivers of people with PIDD. No single strategy works for all people. It is therefore essential for caregivers to take time out to develop the self-understanding needed to learn what works for them.

Future issues of the "IDF Advocate" will include articles on the emotional impact of PIDD and strategies for managing its effects. Readers are invited to send questions and comments about this topic to idf@primaryimmune.org to be considered for discussion. ■

Patient Notification System (PNS) Update

The Patient Notification System (PNS) is a free, confidential, 24-hour communication system providing information on plasma-derived and recombinant product withdrawals and recalls. Led by the Plasma Protein Therapeutics Association (PPTA), the Patient Notification System was developed by the producers and distributors of plasma products with direct input from consumers.

Current Patient Notification System (PNS) Registrants:

Get On Board with Technology – Change Your Notification to Email

As of June 11, 2004 express mail will no longer be an option. If you are currently registered to receive notification via UPS, please contact PNS today at www.patientnotificationsystem.org

or call 1-888-UPDATE-U and change your notification.

Email is instantaneous, trackable and accessible even on travel.

If you are not registered, call IDF at 1-800-296-4433 to obtain enrollment forms.

Don't Delay, Sign Up for the PNS Today.

BLUE JEANS *for* HEALTHY GENES

Have you heard about Blue Jeans for Healthy Genes yet? It's the exciting and new fundraising campaign that lets you educate others about primary immune deficiency diseases AND raise funds for the IDF just by wearing blue jeans to work or school on a specified day.

Response has been tremendous – IDF has already fielded requests from more than 50 individuals who want to sponsor a Blue Jeans for Healthy Genes Day. Upon each inquiry, information packets are mailed out to explain how to host an event. They provide information about IDF for you to present the program to your employer for approval. Information packets are available upon request by contacting Tracy Namie by phone (800) 296-4433 or by e-mail tn@primary-immune.org.

If hosting a Blue Jeans for Healthy Genes Day is not appropriate for your place of work, it may be a great idea for someone you know who works for a different organization. You could use the information packet as a resource to present

the concept to your family members, friends or neighbors who work elsewhere.

Hosting a Blue Jeans for Healthy Genes Day is an easy way for you to help increase awareness of primary immune deficiency diseases...so sign up today!

Help support IDF while implementing a casual dress day in your workplace. Call or email Tracy Namie at 1-800-296-4433 or tn@primaryimmune.org to become a Blue Jeans for Healthy Genes Coordinator.

IDF extends a special thanks to those who have already hosted a Blue Jeans for Healthy Genes Day.

FM Global Insurance, Brecksville, OH
Hirsch Financial Services, Towson, MD
IDF, Towson, MD
Milford Podiatry, Milford, CT
PostHaste Mailing, Annapolis, MD
Primaryimmune Services, Inc, Baltimore, MD
Riverside Elementary School, Westover, WV
SUNY College at Fredonia, Science Departments, Fredonia, NY
Vogel, Chait, Collins and Schneider, Morristown, NJ
ZLB Behring, King of Prussia, PA
ZLB Plasma Services, North Charleston, SC

Conference Call on IGIV Transitioning Educates People Nationwide

Nearly 50 percent of the primary immune deficient patients on IGIV therapy may be required to transition IGIV products in 2004 due to product discontinuation and new product development. IDF strives to keep patients informed about new IGIV products to enable them to maintain their continuity of care and to receive optimal treatment.

On March 31, 2004, more than 260 participants from 41 states called in to a patient education conference call to hear discussion about transitioning IGIV products. Callers were provided with recommendations published by IDF's Medical Advisory Committee and also heard first-hand from patients about their experiences with IGIV product transitioning.

The call was a novel way to educate the community and it received high praise from participants who completed evaluations afterwards. Ninety percent of respondents agreed that the information presented on the conference call impacts their understanding and/or management of their primary immune deficiency disease. And 100 percent indicated that they would participate in another conference call on this topic.

The conference call was sponsored by Bayer Healthcare.

IDF Advocacy at Work for You



Last year, the Social Security Administration (SSA) revisited the medical criteria for evaluating immune system disorders of adults and children for disability benefits. IDF immediately contacted SSA to explain the current problems the primary immune deficiency disease community was facing in obtaining disability benefits. Most patients were being denied disability benefits because the SSA adjudicators did not know or understand primary immune deficiency diseases. Some immune deficient patients went to great lengths, including hiring attorneys, to appeal denials, and many of those attorneys did not understand PIDD. It could take years before a patient would have a hearing before a judge, and then, in most cases, the SSA medical expert had never heard of primary immune deficiency diseases.

During the period of investigation last year, IDF was invited to testify before the Social Security Administration in two hearings held in Philadelphia and San Francisco. Bonnie Doak, Dale Weatherford and Jan Christensen, members of the primary immune deficiency community and volunteer leadership of IDF, participated at the San Francisco meeting and were able to give first-hand testimony of what it is like coping with these rare disorders as a patient or as a family member. Additionally, attorney Bill Leach, of ACCESS, a program that provides free legal counsel for immune deficient patients trying to obtain disability benefits, participated at both meetings. He was a wonderful representative for this community and

was able to supply first-hand knowledge on the difficulties primary immune deficient patients have in obtaining disability benefits and ways to improve the system.

IDF recommendations to the Commissioner on Disability, of the Social Security Administration (SSA)

Adjudicators should:

- Consult with immunologists trained in primary immune deficiency diseases throughout the disability process, especially during the hearing.
- Understand that these disease are marked by recurrent, poorly responsive, severe, or unusual infections. These infections are a result of defects in the immune system.
- Be aware that immune deficiency should be suspected if a person of any age has more than one pneumonia per decade of life, chronic sinusitis requiring antibiotic therapy, chronic bronchitis without history of smoking, increasing number of ear infections after age two years, chronic diarrhea lasting weeks to months or recurrent bacteria infections.
- Understand that infections may occur as frequently as every two to three months.
- Be aware that affected individuals may also have autoimmune diseases and cancer in conjunction with their immune system abnormalities.
- Understand that every infection must be considered a serious infection for this population, since the immune system is compromised.

As a result of IDF's participation in this process, SSA has made the following changes:

1. SSA will include a list of primary immune deficiency diseases to serve as examples in their criteria for disability benefits.
2. SSA will include a list of frequency of infections, rather than types of infections, in their criteria for disability benefits.
3. SSA will train adjudicators to understand primary immune deficiency diseases and use the list of more common diseases to help recognize the diseases, but know that there are other diseases that fall under this category.

IDF remains at the forefront of this issue and will communicate the changes occurring in the disability program. Following below is contact information for the ACCESS program for any patients currently applying for disability benefits or those who have been denied. Attorneys at ACCESS are experts in these diseases and their services are free of charge.

For information on these recommendations, call 1-800-296-4433 to speak with Michelle Vogel, IDF Director of Government Affairs. ■

ACCESS Program

**4710 Eisenhower Blvd., Ste. E3
Tampa, FL 33634
Phone: 888-700-7010
Fax: 813-886-1324**

National Conference 2005

Orlando, Florida June 23-25, 2005

Save this Date! The Third IDF National Conference will be June 23-25, 2005 in Orlando, Florida at Walt Disney World's Contemporary Resort Hotel.

Registration materials will be mailed in January 2005 and will then be available online at www.primaryimmune.org.

Early Bird registration rates are in effect until March 1, 2005. For an

individual, the early bird registration fee is \$95.00 and for a family of up to four the rate is \$175. Conference night room rates are \$95.00 per night. The Contemporary Resort will offer reduced room rates before and after the conference, so make plans now to combine a fun family vacation with the largest conference on primary immune deficiency diseases.

Conference Theme Contest

Do you have a creative theme for the 2005 National Conference at Disney's Contemporary Resort? The contest winner will receive free registration and housing for conference nights. Submit theme ideas by August 31, 2004 to Phyllis Shocket at IDF via mail or email to ps@primaryimmune.org.

For more information, contact Phyllis Shocket at IDF at 1-800-296-4433 or via email at ps@primaryimmune.org.

Philanthropy

IDF extends its gratitude to those who generously contribute to the organization, which enables the IDF to fulfill its mission of education, research and advocacy. For more information call 1-800-296-4433.

Gifts In Memory Of

Florence Arnold
Katherine Austin
Elizabeth Bald
Steven Caplan
Brandon Michael Dahley
Barney Davis
James A. DeChant
Megan Erin Feeley
Delores Goldsmith
Lois Guetz
Grant Kinnear
Ken Kram
H. Willaim Mandelberg
Eric Marder
Delia Miller
Anita Oplinger
Doyle Ramsey
Susan Reker
Susan Marie Reker
George E. Roth
William Roth
David Simpkins
Anna Simpson
Kevin Smith
Dorothy Spalding
David Vetter
Ben Wolf
Lisa Wright

Gifts In Honor Of

Mark Austin
RaeAnn and Nick Barks
Arnold Chait
Anthony William Colon
John Patrick Colon
Christine Densmore &
Alan Druckenmiller
Gini Lea Ennis
Jeremy Ennis
Amanda Flood
Tara Guetz
Norman Hall
Michael L. Karas
The Kollegian Family
Eileen Lackey
Susan Popkin
John Rakckan
Bernie and Shelly Shablott
Thomas Ryan Smith
William H. & Kathleen D. Stouer
Jacob Waugh

Corporate Giving

AAAAI Membership Donation
Abbott Labs
Blair-Huntingdon County CFC
Box Office Barters
Chino Hills Lions Club
Family Practice Residency
Fleet Matching Gift
Franklin Holly Day Committee, Franklin Merchants, MI
Health Advances
IBM
Jewish Foundation
Jones & Richard Inc
Mitsubishi Electric Automotive America, Inc
NY United Way CFC
Profit Portfolio, LLC
Saint-Gobain Corporation Foundation
Sam's Club
United Way of Central MD
World Reach American Express

New IDF Brochures Introduce Foundation to Patient And Medical Professional Audiences

The Immune Deficiency Foundation strives to provide resources for both patients and families and for health-care professionals. Toward that goal, IDF recently produced two new publications – an IDF Overview brochure and a Medical Services brochure.



The IDF Overview brochure is designed for patients and their families and it describes IDF's programs and services.



The Medical Services brochure includes information on services and programs IDF provides to healthcare professionals.

Both brochures may be accessed online at www.primaryimmune.org or you may call 1-800-296-4433 to have one mailed to you.

2004 IDF Research Grant: Dr. John M. Routes Receives Grant to Study Human Herpesvirus 8 in CVID



John M. Routes, M.D.
IDF Research Grant Awardee

The Immune Deficiency Foundation's Annual Research Grant is a national, peer-reviewed competition for researchers pursuing studies in primary immune deficiency diseases. The grant awards up to \$100,000 over a two-year period to a selected recipient dedicated to improving the understanding and treatment of these diseases.

The Immune Deficiency Foundation's 2004 Research Grant has been awarded to John M. Routes, M.D., who is currently completing a two-year study on Herpesvirus 8 in Common Variable Immune Deficiency at the National Jewish Medical and Research Center in Denver, Colorado. The award period runs from January 1, 2004 to December 31, 2005.

Dr. Routes' research, entitled "Human Herpesvirus 8 in Common Variable Immunodeficiency," will

attempt to determine the prevalence of Human Herpesvirus 8 (HHV8) in patients with Common Variable Immune Deficiency (CVID) and other immune deficient diseases. Specifically, Dr. Routes' work will focus on the role of HHV8 infection in impaired B cell signaling in CVID.

Commenting on the grant announcement, Dr. Routes said, "This grant is invaluable in advancing our research in the role of HHV8 in the development of lymphomas in patients with CVID and other primary immune deficiency diseases."

Dr. Routes obtained his M.D. at Indiana University in Bloomington, Indiana in 1997 and he completed his Residency at the Internal Medicine University of Utah in Salt Lake City, Utah. He has dedicated thirteen years at the University of Colorado Health and Sciences Center in Denver, Colorado and is currently an Associate Professor of the Department of Medicine and the Department of Immunology there. Dr. Routes has been appointed a research grant in the Division of Allergy and Clinical Immunology along with his research associate William H. Wheat, M.D., from the National Jewish Medical Center, Denver, Colorado.

Dr. Routes completed the Fred O. Lawson Jr. Fellowship in Clinical Immunology in 1988 and has published close to thirty publications on the study of Immunology and Virology. ■

2004 Family Retreats

Education, Networking and Support in a Family Friendly Weekend

The Immune Deficiency Foundation's first Family Retreat of 2004 proved successful in many ways. Individuals affected by primary immune deficiency diseases and their families from 12 states gathered for the weekend at Woodloch Pines Resort in Hawley, Pennsylvania to learn more about the latest advances in research and treatments from leading experts, while also sharing their own experiences with others facing these rare diseases. Nearly 200 people attended. This was the first of four regional retreats planned for the year.

There was something to do for all ages. Daytime activities on Saturday and Sunday gave adults the opportunity to hear from leading physicians including Kathleen Sullivan, M.D., Ph.D., Ramsay Fuleihan, M.D., Ph.D., Donatella Grafino, M.D., and Robert Hostoffer, D.O. Other speakers included Elyse Murphy, R.N., from ZLB Behring, who spoke about IGIV safety in responding to emerging pathogens.

Register Now!

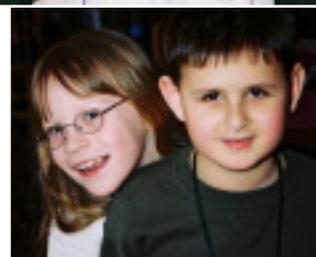
IDF hosts two more Regional Family Retreats, offering families the rare opportunity to attend both scientific and life management skills workshops to hear directly from the experts. Check your mail for a brochure or call IDF at 1-800-296-4433 for more info. The brochure is also available at www.primaryimmune.org.

- **Garrett Creek Ranch
Paradise, TX
September 10-12, 2004**
- **Simpsonwood Conference Center
Norcross, GA
October 22-24, 2004**

Nurses Kim Duff and Linda Schneider spoke about building a better relationship with your healthcare team and Reginald Nettles, Ph.D. discussed coping and life management approaches. Terri Seargent, of ZLB Behring, gave a lecture on insurance issues. On Sunday, a patient panel answered questions posed from others.

While the adults were busy learning, the children were outside in the snow participating in various sporting events in a mini 2004 Winter Olympics, hosted by Woodloch Resort for all of its guests. The IDF 10-12 age group placed second, earning medals for each participant. There was also a special program for teens this year with educational sessions emphasizing the importance of maintaining health insurance, communicating with their physicians and specialists, and team-building.

This marks the sixth year for the family retreats program. The Northwest Retreat occurred June 11-13 in Bend, Oregon. Details on the two remaining retreats follow below. ■



IDF ADVOCATE

Mark your Calendars

IDF Regional Family Retreats 2004

Please see Page 11 for more information.

- Paradise, TX, September 10-12
- Norcross, GA, October 22-24

IDF Local Patient Meetings 2004

IDF plans educational and support meetings in local communities throughout the year. For more information call IDF at 800-296-4433.

- Columbus, OH, June 12
- Green Bay, WI, July 17
- Prospect, CT, July 10
- Seattle, WA, August 28

IDF National Conference 2005

The Third IDF National Conference will be held June 23-25, 2005 in Orlando, Florida. See page 9 for more details.

Combined Federated Campaign (CFC) #9808

IDF BOARD OF TRUSTEES

G. Richard Barr, M.D. <i>Chairman</i>	Rebecca Buckley, M.D. <i>Chairman, Medical Advisory Committee</i>
Kathy Crews, <i>Vice-Chairman</i>	Carol Ann Demaret
Marcia Boyle, <i>Founder Secretary</i>	William Knott
Katherine Antilla	Robert LeBien
Barbara Ballard	Patrick Schmidt
Douglas Bell	Jerry Winkelstein, M.D.
John Boyle, Ph.D.	Jonathan Goldsmith, M.D. <i>Interim President</i>

CHAMPIONS CIRCLE OF SUPPORT

American Red Cross	FFF Enterprises, Inc.
Baxter Healthcare Corporation	Grifols
Bayer Healthcare	Octapharma
	Primaryimmune Services Inc.
	ZLB Behring

The Champions Circle consists of organizations committed to supporting IDF at the highest level. The Circle provides vital resources to fulfill the vision, mission, and core services of the Immune Deficiency Foundation.

Immune Deficiency Foundation
40 West Chesapeake Avenue
Suite 308
Towson, Maryland 21204
Address service requested



Non-profit Org.
U.S. Postage
PAID
Annapolis, MD
Permit No. 273