

IDF ADVOCATE

THE NATIONAL NEWSLETTER OF THE IMMUNE DEFICIENCY FOUNDATION



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A Victory for All

NIH Contract Awards \$12.8 Million Toward Primary Immune Deficiency Disease Research, Administered by IDF



Principal Investigator Hans Ochs, M.D. (right) and Co-Principal Investigator Charlotte Cunningham-Rundles, M.D. Ph.D. launch the USIDNet Consortium.

In September of 2003, an international research network, assembled by IDF, received the largest federal contract ever awarded to study life-threatening primary immune deficiency diseases (PIDD). The \$12.8 million in funding was co-sponsored by the National Institute of Allergy and Infectious Diseases (NIAID) and the National Institute of Child Health and Human Development, which are components of the National Institutes of Health (NIH), an agency of the Department of Health and Human Services.

It was a long road. The process began more than two years earlier when hun-

dreds of IDF volunteers sat down with their members of Congress to plead for more research funding for primary immune deficiency diseases. These determined individuals made the first "Capitol Hill Day" successful by communicating the need for more research. Subsequent Capitol Hill Days in 2002 and 2003 brought even more concerned constituents to rally in Washington, D.C., urging their elected officials to allocate more funding to PIDD research.

On a parallel track, in September 2001, the National Institute of Allergy and Infectious Diseases, one of the National Institutes of Health, and the

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A MESSAGE FROM THE EDITOR

It was certainly a pleasure to meet many patients and their families at the 2003 National Conference. Your warmth and sincerity were overwhelming. Judging by the comments we've received, the Conference proved to be educational, inspirational and helpful. Highlights appear in this issue, on pages 6 and 7.

My colleagues and I heard a number of inspiring patient and family stories and were led to search for ways in which these stories can be shared with others. In the future, we'd like to feature patient stories on a rotating basis on the IDF web site and also in print publications. If you'd like to share your personal story with IDF and the general public, please contact IDF at 800-296-4433 or via email to pm@primaryimmune.org. We look forward to hearing from you.

Pamela Mooring

IDF ADVOCATE

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

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National Institute of Child Health and Human Development (NICHD) convened an Advisory Panel to accelerate research in primary immune deficiency diseases. The Panel learned of successful practices from the European Society for Immunodeficiency (ESID) and reported back to NIH with recommendations based on the beneficial collaboration of those researchers.

The Advisory Panel made three distinct recommendations: the formation of a cooperative network of PIDD investigators; establishing an award mechanism for peer-reviewed, smaller, short-term projects for innovative studies; and the creation of a unified network of experienced investigators to provide leadership and mentoring. A primary goal was to foster collaborative relationships for sharing of information and resources.

Representatives from IDF met with NIAID as early as November 2001 to discuss the requirements of the research consortium. IDF was advised it could submit a proposal and put a concentrated effort into recruiting a team of prominent researchers in the field of primary immune deficiency diseases. Many in-person and teleconference meetings followed.

On October 3, 2003 NIAID announced that the five-year, \$12.8 million contract was awarded to the Primary Immunodeficiency Research Consortium (doing business as USIDNet, short for the U.S. Immunodeficiency Network), and IDF would provide administrative support.

Hans Ochs, M.D., University of Washington School of Medicine, Seattle, Washington, leads USIDNet as the Principal Investigator. He heads

a seven-member steering committee that will select the research proposals to receive grants, based on peer reviews from a scientific advisory panel. The request for proposals is planned for late 2003 and will be broad in scope. Potential studies could include the molecular basis of PIDD, gene transfer, diagnostic screening tests and genotype-phenotype studies.

A large component of the contract involves expansion of the IDF-maintained patient registries that resulted from NIAID funding awarded in 1993 and 1997. The registry will be accessed by researchers via a secure web site that ensures privacy of the cases that are registered by physicians. A cell line repository based at Coriell Institute for Medical Research in Camden, New Jersey, will include DNA samples of PIDD patients included in the registry.

Anthony S. Fauci, M.D., Director of NIAID, commented on the announcement, saying, "Until now, a relative scarcity of study subjects has limited a researcher's options for investigating these lesser known diseases." In the past, samples collected by individual researchers remained with these researchers. Since patient populations for some primary immune deficiency diseases is in the hundreds or thousands, there was never a large quantity of DNA samples. By forming this single repository, researchers around the world will have access to a much larger number of samples for their approved studies.

"A fundamental element of IDF's mission has been to fund research," said IDF Vice President of Medical Affairs Jonathan Goldsmith, M.D. "This federal funding will enable IDF and the country's finest researchers to investigate new approaches. We anticipate great results

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for diagnosis and treatment for our community and the world.”

IDF Founder Marcia Boyle summed it up best when she hailed the award as “a victory for all.”

Lead Investigators

Principal Investigator:

Hans Ochs, M.D.

Professor of Pediatrics and Director of the Immunodeficiency Clinic at the University of Washington School of Medicine, Seattle, WA

Co-Principal Investigator:

Charlotte Cunningham-Rundles, M.D., Ph.D.

Professor of Medicine, Pediatrics and Immunobiology at Mount Sinai Medical Center, New York, NY

Steering Committee:

Rebecca Buckley, M.D.

J. Buren Sidbury Professor of Pediatrics and Professor of Immunology & Chief, Pediatric Allergy/Immunology, Duke University Medical Center, Durham, NC

Mary-Ellen Conley, M.D.

Federal Express Professor of Pediatrics, St. Jude Children's Research Hospital, Memphis, TN

Alain Fischer, M.D., Ph.D.

Director of the Unite' d'Immunologie et d'Hematologie Pediatriques Hopital Necker-Enfants Malades, Paris, France

Raif Geha, M.D.

Harvard Medical School
Boston, MA

Jennifer M. Puck, M.D.

Director of the Genetics and Molecular Biology Branch, National Human Genome Research Institute, NIH, Bethesda, MD

Richard E. Stiehm, M.D.

Professor of Pediatrics, Chair of Academic Affairs, Department of Pediatrics, Mattel Children's Hospital at University of California Los Angeles, Los Angeles, CA

The USIDNet consortium will be administered by:

Jonathan Goldsmith, M.D.

VP Medical Affairs, Immune Deficiency Foundation, Towson, MD

Don Weinapple, C.P.A.

CFO, Immune Deficiency Foundation, Towson, MD

Primary Immunodeficiency Diseases Registry (PIDR) Program

The Primary Immunodeficiency Diseases Registry (PIDR) program established and now maintains a registry of primary immune deficiency patients in the U.S. The registry provides information and identifies samples to be used in clinical research, which is vitally important since many of these diseases have such low incidences that samples are severely limited in quantity.

Begun in 1993 as a registry on Chronic Granulomatous Disease, the registry expanded in 1997 to include seven more disease states, including:

- Chronic Granulomatous Disease
- Common Variable Immunodeficiency Disease
- DiGeorge Anomaly Syndrome
- Hyper IgM Syndrome
- Leukocyte Adhesion Defect
- Severe Combined Immunodeficiency Disease
- Wiskott-Aldrich Syndrome
- X-linked Agammaglobulinemia

These ongoing registries will become a part of the research consortium, USIDNet. Patients are registered anonymously through their physicians by case number. Living as well as deceased patients are eligible to be included. Patients can share this information with their doctor. **Physicians who need information on how to enter patients, or researchers who would like to access one or more of the registries, should contact KK Marino, Director of Medical Registries, at the IDF.**

Participation by physicians, especially those who have responded to IDF's recent one-page Survey of U.S. Physicians, is greatly appreciated. That information will help expand the registries again and is a valuable resource in ongoing research.

FluMist™ Poses Risk to Patients with Primary Immune Deficiency Diseases

Although fall is barely here, public health authorities are gearing up for the Influenza season due to make its annual appearance starting in October and continuing through the winter months. Influenza, known more commonly as “the flu,” can cause very serious respiratory illnesses in normal people. Those with primary immune deficiency diseases (PIDD) may be at increased risk for the flu and experience the more serious complications. The major goal of the public health approach to flu is to vaccinate as many people as possible with the current version of the vaccine which contains the latest form of the flu viruses, known as types A and B. Vaccination leads to the production of antibodies and protection against influenza infection.

This year for the first time, in addition to the killed flu vaccine available in prior years, a live attenuated flu vaccine, FluMist™, has been licensed by the US Food and Drug Administration. The two type A and one type B influenza strains in the vaccine are weakened through rearrangement of the viral genetic material. FluMist is administered intranasally using a small syringe-like device to deliver the liquid containing the three flu strains. Clinical trials have been conducted with FluMist for a number of years and the FDA has licensed it for use in healthy children

and adults five to 49 years of age. Public health authorities and others are targeting children, a major reservoir for flu viruses, for immunization with FluMist. Application by nasal spray may make this vaccine more acceptable than the traditional flu shot.

FluMist is a live virus vaccine and should not be taken by those with PIDD. Although there is no specific information available, it is anticipated that if a person with PIDD received FluMist (s)he would more likely develop complications. In fact, Medimmune Vaccines, Inc., the maker of the vaccine has stated that: “As with other live virus vaccines, FluMist™ should not be administered to individuals with known or suspected immune deficiency diseases such as combined immunodeficiency, agammaglobulinemia, and thymic abnormalities and conditions such as human immunodeficiency virus infection, malignancy, leukemia, or lymphoma.”

Although you or your family member with PIDD can avoid FluMist vaccination, there are two other potential ways in which you or your family member could become infected with the flu vaccine strains. During a clinical trial with FluMist in a day care center, there was documented spread from vaccinated children to unvaccinated children. Viral shedding following the administration of FluMist typically

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FluMist™ intranasal applicator and packaging: This product poses risk to PIDD patients.

Important Points Regarding FluMist™ for Those Affected by PIDD

FluMist™ continued from page 4

continues for about a week on the average, but may be as long as three weeks. The risk of transmission in the day care setting was estimated at 2.4 percent, or one in approximately 42. The risk could be higher if different children in the center receive the vaccine at different times over the fall.

Healthcare workers who receive FluMist may present a second possible way for a person with PIDD to become infected with the flu vaccine strains. Although there is no data about transmission of the live vaccine virus from vaccinees to immunocompromised contacts and subsequent development of disease, the Centers for Disease Control and Prevention has stated that the flu shot is preferred over the live FluMist vaccine for physicians, nurses, family members, or anyone else coming in close contact with anyone with a weakened immune system.

IDF's Medical Advisory Committee formed a Working Group to evaluate FluMist and has stated that it may be appropriate for some children with PIDD to receive antiviral agents as a preventive measure while their classmates are receiving FluMist this fall. One of these antiviral agents, Tamiflu® (Roche), has been approved by the FDA for prevention of types A and B Influenza in those 13 years of age and

older. It is given once daily for up to 42 days and may also have benefit if given within two days of exposure to influenza strains. However, there are no studies of the use of Tamiflu in PIDD patients exposed to FluMist influenza strains.

The Working Group has also advised that school authorities may want to advise their pupils if FluMist is being administered in the school system. This information may be especially useful to those with T cell or combined T and B cell immune deficiencies.

People with PIDD may choose to receive the inactivated influenza vaccine shot. This is the killed version of the vaccine and will not cause the flu! The only risks of receiving the shot are soreness at the injection site, and less often fever, tiredness, muscle aches, and headache. Those allergic to eggs should not receive the vaccine shot, 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. Your family members should seriously consider receiving the killed version of the flu vaccine to reduce the risk of bringing the flu virus home to their PIDD family member.

1. Because it is a live virus vaccine, people with primary immune deficiency diseases should NOT receive the FluMist vaccine.

2. The FluMist vaccine is not recommended for close contacts of primary immune deficient patients.

3. Primary immune deficient patients should talk to their doctors to see if it may be advisable to receive preventive medicine to avoid becoming infected with the FluMist strains of the flu.

4. Primary immune deficient patients exposed through close contact to FluMist, should see their doctor immediately, as (s)he may advise a treatment medicine.

5. School authorities may want to advise their immune deficient pupils if FluMist is being administered in the school system. This information may be especially useful to those with T cell or combined T and B cell immune deficiencies.

6. Family members and healthcare workers in close contact with immune deficient patients should be advised to receive the traditional killed virus flu shot, rather than the FluMist vaccine.

Connecting, Learning, Living

Second IDF National Conference Brings Primary Immune Deficient Community Together

The National Conference is the only meeting of its kind to bring together individuals and families affected by primary immune deficiency diseases. Attendees of the Second IDF National Conference learned about scientific advances in the diagnosis and treatment of PIDD and gained the skill and support to manage their health care.

This year's meeting built on the success of the first Conference in 2001,

adding sessions, information, speakers and activities. More than 1,300 patients, families, healthcare providers, government and industry representatives came together at the Marriott Waterfront Hotel in Baltimore for the two-day event.

Patients and their families again expressed the emotional depth they felt by meeting others with similar conditions. Said one, "I have only met two other people with CVID and it felt so great to see so many healthy,

happy-looking, uplifting people." By Friday, a bulletin board posted names and diagnoses from individuals seeking others in their region with whom to share their experiences.

Educational Sessions

More than 27 scientific sessions led by world renowned physicians and researchers and gave participants the opportunity to learn more

about primary immune deficiency diseases, their causes, symptoms and treatment options. Specific Diagnosis Sessions addressed seven different disease states and the Scientific Sessions discussed current treatment methods. Question-and-answer periods followed nearly every session. A half-day professional program was offered for healthcare providers.

Patient Treatment Survey

The IDF recently conducted an in-depth patient survey to provide a comprehensive portrait of the treatment of those with primary immune deficiency diseases (PIDD). The results were presented June 20 at a breakfast seminar during the Conference. Results from the survey indicated that there is an average nine-year delay from onset of symptoms to diagnosis and that PIDD, which were once thought to be primarily a pediatric problem, now affect more adults than children.

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Advocates Take Message to Capitol Hill



Senator Landrieu (left) accepts IDF award, joined by constituents and IDF volunteers Gail and Sydney Nelson.

One day prior to the IDF National Conference, patients and their families stormed the nation's capitol during the third annual IDF Capitol Hill Day. These determined advocates voiced support for two important initiatives: NIAID's Primary Immunodeficiency Disease Consortium and Medicare coverage of home infusion of IGIV.

Approximately 400 family members traveled by bus to Washington, D.C. on Thursday June 19 to meet with their

Senators and Representatives on these important issues as well as state agendas. The volunteer contingent concluded the day in the city by celebrating as IDF awarded Senator Mary Landrieu (D-La.) the Public Policy Leadership Award. Sen. Landrieu received the award for doubling funding at the National Institutes of Health and for increasing public awareness and monitoring of primary immune deficiency disease threats through the NIH and U.S. Centers for Disease Control and Prevention.

Conference continued from page 6

Results of the survey were shared with media outlets across the country and received over 81 million impressions. The findings provide useful information in determining patient concerns and needs. This information will help direct the IDF's future programs.

IDF Extravaganza

Closing the weekend with fun for everyone, the IDF Extravaganza provided live music, carnival games and food, and a visit from a princess who offered a peek at the magical Conference planned for 2005 in Orlando, Florida. The children were enthralled by the visit and lined up to speak to, and be photographed with, the princess. The Extravaganza was held under the huge awning of the Pier 6 Concert Pavilion waterside at the Baltimore Harbor.

Youth Activities

Children who attended the Youth Program toured Baltimore's celebrated Inner Harbor attractions including the Maryland Science Center and the National Aquarium in Baltimore. On-site programming for the Youth Program and child care were provided free of charge to registered conference attendees.

IDF Celebration Banquet

Conference participants packed the Grand Ballroom Friday evening for the IDF Celebration Dinner, where Dr. Jerry Winkelstein was honored for his 22 years of service. Recognized for their support were Silver Sponsors Alpha Therapeutic Corporation, American Red Cross, Octapharma and ZLB Bioplasma Inc. Platinum Sponsors included Aventis Behring, Baxter Healthcare Corporation, Bayer Corporation, FFF Enterprises, Inc. and Grifols. IDF President Tom Moran was also lauded at Pier 6 for seven years of leadership at IDF.

Founder Marcia Boyle launched the Endowment and Capital Campaign aimed at raising \$5 million over the next five years. Patrick Schmidt, President of FFF Enterprises presented Ms. Boyle with an oversized check representing the inaugural gift of the campaign—\$1 million. For more information on the Endowment campaign visit www.primaryimmune.org.

The feelings of many were summed up by one attendee, who wrote, "It meant so much to meet people 'like me' and to gather so much helpful and needed information, and to receive hope for the future!"



Opposite Page, Left: (L-R) Jerry Seigel, RPH, FASHP, Jerry Winkelstein, M.D. and John Boyle, Ph.D. discuss the IDF survey results. **Top:** One of many families taking in music and food at the IDF Extravaganza. **Above:** John and Marcia Boyle are interviewed by Channel 13 Baltimore News Health Reporter Kellye Lynn.

Participate in the IDF Online Survey of Patients and Caregivers

This national survey of patients and caregivers for those with primary immune deficiency diseases can be accessed on the IDF homepage. Click on the "Participate in our National Survey" link under "Quick News" at www.primaryimmune.org. The survey results will be used to help IDF identify key areas in which to expand educational programs, events and support.

Your Voice Counts:

Grassroots Advocacy for the Primary Immune Deficiency Diseases



Any advocacy network is only as powerful and influential as its members and the actions they take, both individually and collectively. There are many different ways for people to get involved in grassroots advocacy, but the important thing is to participate.

A lobbying background is not required. All that is needed is personal experience, factual information to substantiate claims, and knowledge of who the key decision-makers are and what is most likely to influence them.

Those living with PIDD, their family members and their healthcare workers all have valuable information that can help elected officials and policy makers do their jobs better. First-hand experience is important feedback for officials who rarely get the chance to visit patients or programs themselves. When constituents communicate with their elected officials about what they think is important for people living with PIDD, they are engaging in grassroots advocacy. This exchange benefits the policy-makers and the advocates. Personal experiences are shared with someone who is in a position to increase funding for PIDD research, increase access to specialty care, include coverage for IGIV, increase eligibility for disability

benefits, expand newborn screening for SCID and provide educational services on the dangers of live virus vaccines or immunizations for PIDD patients.

Often, advocates work in concert with IDF to carry important messages to as many communities as possible. They may help disseminate health advisory information or tell their personal story to the media. Advocates who reach others in this way help communicate the message more strongly by using more voices.

IDF actively advocates as an organization on behalf of the primary immune deficiency disease community. IDF works for increased funding for PIDD research and it strives to protect patients and their families through public policy. IDF, as does any organization, needs the support of those it represents. There are numerous and varied vehicles to carry important messages to Congress. By working with IDF, supporters may take part in a Capitol Hill Day or heed an Action Alert on the IDF web site and call or write elected officials to voice an opinion on an important piece of legislation.

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First Capitol Hill Briefing Packs House

The Immune Deficiency Foundation held its first Capitol Hill Briefing on October 31, 2003 in the U.S. Capitol Building. It was standing-room only, as Congressional staffers, patients and family members, industry representatives and the media packed the room. Staffers came to learn more about primary immune deficiency diseases and policy issues affecting the PIDD community, specifically the importance of access to all brands of IGIV, choice where patients receive their infusions (Medicare home infusion), and increased funding for research at the National Institutes of Health. The briefing featured presentations from patients and patient advocates as well as IDF staff: Jonathan Goldsmith, M.D., Vice President of Medical Affairs; Jennifer Scharpf, Vice President of Patient Services; Candace Steele, Vice President of Marketing and Communications; Melissa Schweitzer, Director of Patient Advocacy and Genetic Services; and Michelle Vogel, Director of Government Affairs.

States represented were: Colorado, Florida, Georgia, Illinois, Louisiana, Maine, Massachusetts, Montana, New Jersey, New York, Nevada, North Carolina, Ohio, South Dakota, Tennessee, Texas, Wisconsin, and the District of Columbia. Key healthcare staffers from the following important Senate and House Committees were at the briefing: Senate Finance Subcommittee on Health; Senate Health, Education, Labor and Pensions Committee; Senate and House Appropriations Subcommittee on Health; House Ways and Means Subcommittee on Health; House Energy and Commerce Subcommittee on Health; and House Education and the Workforce Committee.

This briefing was the first step in helping to educate policymakers and their staff about the needs of the primary immune deficiency community.

Grassroots continued from page 8

For many years, IDF has engaged in lobbying efforts on Capitol Hill. Now IDF will launch a Grassroots Advocacy Network to mobilize PIDD providers, advocates, persons affected by PIDD and industry partners throughout the country to promote sound policy and legislation. Through participation in the IDF Grassroots Advocacy Network, people who care about PIDD can become directly involved in policy-making and learn to advocate effectively at the local, state and federal levels of government. IDF helps those interested in becoming a member of the Advocacy Network learn and use new advocacy skills. Collectively, IDF participants are part of a movement to create change.

There are several programs through which individuals can flex their advocacy muscles.

- Coming soon: IDF Grassroots Advocacy Conference: Briefings on current and emerging PIDD policy issues, as well as skills-building workshops.
- Annual IDF Capitol Hill Day: Combining one-on-one patient and family meetings with federal representatives and an award ceremony for a member of Congress who has served as an IDF advocate.
- District Patient Meetings: IDF offers information and assistance to members who would like to organize meetings with elected officials in their local district offices so that legislators hear directly about issues that are important to people living with PIDD.
- “Action Alerts” on the IDF web site: Advocates can find “Action Alerts” on breaking policy developments that include suggestions for urgent grassroots action.

IDF continues to organize dynamic events that empower participants and influence policy. For more information on how you can get involved in IDF's advocacy efforts, please contact Michelle Vogel, Director of Government Affairs, at mv@primaryimmune.org or 1.800.296.4433. More information on IDF and primary immune deficiency diseases may be found online at www.primaryimmune.org.

Distinguished Leaders in New Roles

Jerry Winkelstein, M.D. Steps Down and Rebecca Buckley, M.D. Assumes Leadership of MAC



The Medical Advisory Committee (MAC) advises IDF on medical issues, helps prioritize patient programs, evaluates research proposals for funding and networks with managed care and pharmaceutical organizations. The MAC also forms Working Groups to provide clinical recommendations for PIDD patients in response to potentially harmful products, live vaccines or outbreaks of illness.

20 Years of Guidance by Dr. Jerry Winkelstein

After more than 20 years of dedicated service, Dr. Jerry Winkelstein stepped down as Chairperson of IDF's



Medical Advisory Committee (MAC). Wishing to remain acutely involved with IDF, Dr. Winkelstein is serving on the IDF Board of Trustees.

Dr. Winkelstein began his medical career in the residency program at the Johns Hopkins Hospital and then served for two years in the Indian Health Service in Bethel, Alaska. He returned to Johns Hopkins, assuming the position of Director of the Division of Allergy and Immunology. He also serves as Professor of Pediatrics, Medicine and Pathology.

It was at Johns Hopkins that Dr. Winkelstein met Marcia and John Boyle, who requested he join them in

founding the IDF. The foundation established the Medical Advisory Committee and under the leadership of Dr. Winkelstein medical programs such as the Fellowship Grant, the Consulting Immunologist program, the Visiting Professor program and the Research Grants program were established. With the assistance of Dr. Winkelstein, IDF was awarded a National Institutes of Health (NIH) contract to establish the Primary Immune Deficiency Diseases Registries. He serves as Principal Investigator for this project. During his tenure, groundwork was laid for the proposal for an NIH/NIAID research contract for the study of primary immune deficiency diseases, which was recently awarded to USIDNet. He currently serves as an expert member of the Health and Human Services Committee on Blood Safety and Availability.

Dr. Winkelstein's tremendous contributions have greatly benefited the PIDD community and IDF.

Dr. Rebecca Buckley Takes the Helm

Rebecca Buckley, M.D., is the J. Buren Sidbury Professor of Pediatrics and Professor of Immunology at Duke University Medical Center in Durham, North Carolina. She is also the Chief of the Division of Pediatric Allergy and Immunology.

Dr. Buckley received her undergraduate degree from Duke University and earned her M.D. at the University of North Carolina School of Medicine in Chapel Hill, North Carolina. She

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Manufacturers' IGIV Donations Save Lives

IDF applauds American Red Cross, Grifols, and ZLB Bioplasma Inc. for their charitable donations of IGIV for IDF's Compassionate Care IGIV Program. Over the past year, American Red Cross and ZLB Bioplasma Inc. have consistently supplied IDF with free IGIV to assist individuals who are not taking their prescribed IGIV due to health insurance or financial barriers. Recently, Grifols, a manufacturing company new to the United States, provided IDF with an extremely generous donation of product for the program. IDF wishes to express our extreme appreciation to these companies for their continuing commitment to the program.

To learn more about this temporary assistance program, contact IDF at 800-296-4433. Qualification for this program requires coordination with the patient's physician and is ultimately determined after review of appropriate documentation by IDF's Vice President for Medical Affairs.



Remembering an Immunology Pioneer

MAC Chair continued from page 10

served her internship, residency, fellowship and postdoctoral training at Duke University Medical Center.

Dr. Buckley is an expert in the normal and defective development of human T and B cells. Her work has focused on a number of human primary immune deficiency diseases. She was the first to describe the Hyper IgE syndrome and is an expert on Severe Combined Immune Deficiency (SCID), having evaluated more than 165 SCID patients.

Dr. Buckley has served on the IDF Medical Advisory Committee since 1982. She has served on national councils and committees, been involved in a dozen scientific and professional societies and has held numerous editorial posts. Dr. Buckley has served on NIAID's Task Force on Immunology, its Board of Scientific Counselors, and currently sits on the Data and Safety Monitoring Board.

All at IDF welcome Dr. Buckley as the new Chairperson of the MAC and look forward to her visionary leadership.

Philanthropy

Gifts In Memory Of

Jeanie Brody
Dr. Donald Carrow
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The Immune Deficiency Foundation sadly acknowledges the passing of Robert A. Good, M.D. on June 13, 2003.

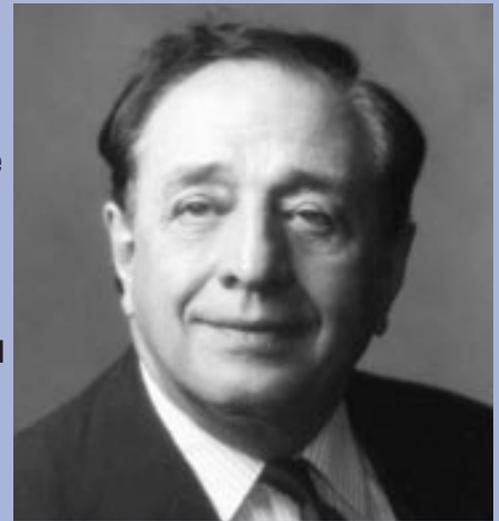
Dr. Good devoted his life to serving as a physician, researcher and teacher.

Often referred to as the "father

of modern immunology," Dr. Good performed the first successful bone marrow transplant in the world in 1968. He was the President and Director of the Sloan-Kettering Institute for Cancer Research and Director of Research at Memorial Hospital in New York for nearly a decade. Dr. Good served All Children's Hospital as Physician-in-Chief and directed the Division of Allergy and Clinical Immunology. Under his direction, the hospital developed a Bone Marrow Transplantation Unit and clinical programs in pediatric allergy/immunology, pediatric rheumatology and pediatric HIV. He was also a Distinguished University Professor at the University of South Florida, College of Medicine.

In addition to earning a Bachelor's degree, an MB, and dual M.D. and Ph.D. degrees, Dr. Good was also awarded more than a dozen honorary degrees from institutions worldwide. He authored or co-authored over 2,000 publications and was a leader in numerous professional societies.

Dr. Good's legacy lives on through the hundreds of physicians he trained or mentored, many of whom are practicing and teaching throughout the world. He will be missed by all who knew him.



Robert A. Good, M.D., Ph.D., D.Sc.
1922-2003

ROBERT A. GOOD, MD, PHD, DSC
1922 - 2003

IDF ADVOCATE

IDF National Conference 2005

IDF will hold the Third National Conference June 23-25, 2005 in Orlando, Florida.

Local Programs 2004

Stay tuned for more information on the IDF Family Retreat Weekends planned for 2004 and Regional Patient Meetings that provide education and support for patients and their families. For more information call the IDF at 800-296-4433.

Donate Your Vehicle

Donate your vehicle to IDF and receive a tax benefit. IDF accepts cars, trucks, boats, recreational vehicles (RVs) and trailers. Donations of vehicles are tax deductible – you'll get your receipt directly from the tow driver upon pick-up of the car, title and keys. Contact IDF at 800-296-4433 for additional information. Additional ways to give are listed on the web site www.primaryimmune.org

**Please Support the 2003 IDF Annual Giving Program
CFC #9808 (Combined Federated Campaign)**

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