

## Yankees Baseball World Series Champs Take To The Links To Support IDF and Alpha One

**S**pring training will take on an added dimension when Shane Spencer and other New York Yankees players trade their baseball bats for golf clubs and take to the links to "Drive for the Cure." This second in a series of charity golf tournaments coordinated by Lisa and Woody Williams will be held at the prestigious Hunter's Green Country Club in Tampa, Florida on February 19, 2001. A joint benefit for the IDF and the Alpha One Foundation, proceeds from this spectacular event will fund much needed medical research and provide

patient support programs to individuals affected by primary immune deficiencies and Alpha1-Antitrypsin Deficiency.

Founding sponsors of the event are Aventis Behring and FFF Enterprises. Presenting sponsors include AlphaNet, Bayer Corporation, and Primary Immune Services, Inc. The tournament features a 1PM shotgun start, tee prizes for all participants, including a windshirt and leather sports bag, a dinner and an auction. Don't miss this great opportunity to have fun with your friends while supporting important research that will find cures and save lives.



*To purchase a foursome of golf at the Tampa tournament, contact Elizabeth Lee at IDF at (800) 296-4433. The Florida Chapter of IDF is hosting the tournament and volunteers are needed to help out. If you are interested in volunteering, please contact Gail Moore at (863) 519-0191 or Lynne Scott at (561) 398-6163. ■*

### FEATURED THIS ISSUE

- **IDF COMMEMORATIVE MESSAGE** Founder and chairman Marcia L. Boyle provides a retrospective look at patient service and medical progress at IDF
- **ANNIVERSARY APPEAL** Show your support for IDF by celebrating the Foundation's "Twenty Years of Progress" with a generous gift
- **RESOURCE GUIDE** From patient registries to information and referral services, educational scholarships to clinical trials, patient notification of product recalls and withdrawals to representing the interests of blood safety and availability, IDF does it all for you
- **IDF/NOVARTIS SCHOLARSHIPS** Applications from promising undergraduate students with a primary immune deficiency disease must be received by March 31, 2001

### FIRST IDF NATIONAL CONFERENCE

We have a winner! Congratulations to Jane Coumos of Mayfield Heights, OH, who will be awarded free registration, hotel accommodations and transportation to IDF's First National Conference for submitting the winning theme "Primarily For You." The 2001 Conference will take place on June 21-23 at the Marriott Waterfront Hotel at Baltimore's Inner Harbor, and opens with a party at the National Aquarium in Baltimore. In addition to providing a wealth of information about specific diagnoses, scientific advances in treatment and therapies, and innovations in disease management, there will be many opportunities to interact with others affected by primary immunodeficiency and a youth program for children.

This meeting is the first of its kind to bring together individuals affected by primary immunodeficiency diseases. Platinum Sponsors are Aventis Behring and Bayer Corporation. Additional support is provided by Alpha Therapeutic Company, American Red Cross, Baxter Healthcare Corporation and FFF Enterprises.

*Thank you to all who have contributed their ideas to this first-ever effort. Registration materials for the IDF National Conference are now available. Detailed program descriptions and information on the hotel is included. If you have any questions about the conference, contact Jennifer Bass or Elizabeth Lee at IDF at (800) 296-4433, or visit our website at [www.primaryimmune.org](http://www.primaryimmune.org) for Conference updates and registration information.*



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

# Twenty Years of Patient Service and Medical Progress at IDF

**By Marcia L. Boyle, Chairman, Board of Directors**



As the chairman and founding member of the Immune Deficiency Foundation, I join IDF's volunteers and professional staff in celebrating our 20th anniversary. Personally, I am both overwhelmed and humbled by IDF's achievements over the years.

You may recall a time when there were few treatments for many primary immune deficiency diseases, and the treatments that were available were painful and much less effective. When my son was diagnosed with agammaglobulinemia in 1978, there was no patient organization for primary immune diseases. No educational materials, advocacy or support programs existed for patients, and there were few programs of medical education. A small group of families and friends decided change was needed, and in December of 1980, we founded IDF as the first national patient organization devoted to research and education to improve the treatment of patients with primary immune deficiency diseases.

Looking back over the past 20 years, we feel a real sense of accomplishment that a sustained and growing organization has evolved from its origins on a "kitchen counter." We can point to several achievements that have positively impacted the lives of patients and have helped improve the understanding and treatment of these serious diseases.

First and foremost, we

have created a national focus for these rare, but significant diseases, and an organization for both patients and medical professional to turn to with questions and problems. In response to the ongoing need for patient support on a myriad of issues, including health insurance, living with these diseases, access to care and more, we created a national office as the first line of defense and a network of local groups that offer educational meetings and telephone support. A quarterly newsletter, patient and professional handbooks, and an online presence at [www.primaryimmune.org](http://www.primaryimmune.org) have been designed and maintained to keep us all up-to-date on current issues and activities.

And, since one of our most important goals is to improve the treatment of primary immune deficiency diseases, we have established a national medical program that has been an ongoing and highly significant focus of IDF. Under the auspice of IDF's Medical Advisory Committee, we have sponsored a number of important research grants such as the Molecular Diagnostic Laboratory and a host of medical symposiums, supported post-doctoral fellows to research and train in the clinical care of patients, organized programs of visiting professors and consulting immunologists, and managed the first national registry for a primary immune deficiency disease-Chronic

Granulomatous Disease-through a contract with the National Institutes of Health. The success of this registry has led NIH to contract IDF to manage seven more, for a total of eight national registries! Already, these registries have gathered a great deal of important clinical information on a group of rare diseases.

In 1997, IDF's advocacy program took on a heightened importance. A nationwide shortage of IGIV, essential to the lives of many immune deficient patients, was seriously impacting treatment. IDF swiftly responded with programs to ensure that no primary immune deficient patient should go without treatment or have treatment delayed. With the cooperation of all U.S. plasma fractionators, IDF introduced the Safety Net Program which ensures an emergency supply of IGIV,

and the Patient Notification Program which guarantees that notices of product recalls or market withdrawals reach primary immune deficient patients and their families. IDF has worked closely with the U.S. Food and Drug Administration (FDA) and medical community to achieve medical prioritization of IGIV. And, in order to expedite the licensing of new products, IDF has spurred the FDA and its medical advisors to develop a new protocol for clinical trials of IGIV. Through the Foundation's subsidiary, Primary Immune Services, Inc., IDF is currently

conducting two clinical trials of IGIV. Much of IDF's success in this arena results from the personal testimonies of patients and physicians, and statistics gleaned from IDF's national patient surveys.

Although our 20th Anniversary presents an opportunity to celebrate our abounding organizational successes, we all know that there is still much to be done. As IDF goes forward, we are looking at programs that will better meet the needs of patients in the years to come. We know that access to specialists and affordable care is still an overwhelming problem, and that we must continue to involve physicians, industry, and government if there is to be continued improvement in this critical area. We must, and we will, persevere in our efforts to ensure the safety and availability of current treatments.

At the same time, we are now living through a revolution in the genetic and molecular understanding of human diseases. IDF must continue to seek out opportunities to partner with its medical community, the NIH, and industry to focus on areas of research that could dramatically improve the diagnosis and treatment of primary immune deficiency diseases. We believe that a focused and concerted effort can accelerate the development of improved treatments at the molecular and genetic levels.

Finally, while we wish for the day when all primary immune deficiency diseases will be cured and we will no longer need the Immune

**CELEBRATING**  
1998-2000  
**20 • YEARS**  
OF PROGRESS & LEADERSHIP

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Deficiency Foundation, we know that day is not around the corner. Therefore, we hope that a new generation of volunteers will emerge to help IDF to continue to grow and provide service and leadership. We look forward with great anticipation to our First National Conference in Baltimore, Maryland on June 21-23, 2001. This event will mark the first time when patients, families and medical professionals from across the country will come together to learn about treatments, medical advances, problems that affect patients, and to interact with others who are facing the same issues. I hope that many of you will be able to attend and look forward to welcoming you.

In closing, I would like to extend my personal appreciation to the members of the IDF Board of Trustees, local program leaders and volunteers, the members of the Medical Advisory Committee and other IDF medical programs, the representatives of industry who have helped support so many of our critical programs, to our professional staff, and to all of you who have supported IDF's efforts over the past 20 years. Thank you all for helping IDF make a difference. ■

ANNIVERSARY APPEAL

Now, IDF is asking for your help. Please support our Foundation and its future efforts with a very special 20th Anniversary gift.

Today, thanks to the continuing efforts of the Immune Deficiency Foundation, thousands of individuals and their families can count on our ongoing support of groundbreaking research, our specialized education programs, and our tireless advocacy at local and national levels.

With you as our partner, we look forward to additional achievements in the months and years ahead. We're especially busy planning IDF's first-ever National Conference on June 21-23, 2001. This Conference is an unprecedented event where patients and family members, medical leaders, and researchers will gain a deeper understanding of primary immunodeficiencies, learn new techniques for managing the disease, and make new contacts for peer support.

Please join us in Celebrating Twenty Years of Progress with a generous anniversary gift!

Enclosed is my anniversary gift to help support the Immune Deficiency Foundation.

- Individual \$25 Family \$50 Professional \$100 Patron \$500 Charter \$1000 Other \$\_\_\_\_\_

METHOD OF PAYMENT

\$\_\_\_\_\_check enclosed. Make check payable to Immune Deficiency Foundation. Your gift is tax deductible.

Please bill my gift to: MasterCard Visa

Card # \_\_\_\_\_ Expires \_\_\_\_\_

Name as appears on card \_\_\_\_\_

My gift will be matched by \_\_\_\_\_

Amount \$ \_\_\_\_\_ Signature \_\_\_\_\_ (Please enclose matching gift form)

Please return to: IDF at 40 W. Chesapeake Ave., Suite 308, Towson, MD 21204.

IDF Resource Guide

Please call the IDF National Hotline at (800) 296-4433 for more information on the following programs:

Information/Services for patients and families

- Patient and Family Handbook for the Primary Immune Deficiency Diseases; Our Immune System; How to Keep an Infusion Log; Primary Immune Deficiency Diseases: An Overview Brochure; "Day in the Life" CD-ROM National Newsletter of the Immune Deficiency Foundation IDF Website - www.primaryimmune.org Annual Student Scholarships for post-secondary education PSI Safety Net Program - A reliable, emergency supply of IGIV for patients and physicians 25 local programs providing peer support to patients and their families

Programs/Materials to share with your physician

- The Clinical Presentation of the Primary Immunodeficiency Diseases - A Primer for Physicians; Primary Immune Deficiency Diseases - A Guide for Nurses; "Clinical Focus" (professional education monograph) Consulting Immunologist Hotline (877) 666-0866 - Provides physicians a free consult or second opinion on primary immunodeficient patients Visiting Professor Program - Offers Grand Rounds and Clinical Presentations at medical institutions throughout North America Annual Fellowship Competition - For researchers pursuing post-doctoral studies relating to primary immunodeficiency diseases National Patient Registries of Primary Immunodeficiency Diseases - Enroll through your physician Molecular Genetic Diagnostic Lab - Offers free molecular, carrier, and prenatal diagnosis

Other ways that IDF helps

- Works with government agencies and industry to help ensure access to specialized care and proper insurance reimbursement Represents primary immunodeficiency diseases on the FDA Blood Products Advisory Committee and the US Department of Health and Human Services Committee on Blood Safety and Availability Promotes the medical prioritization of IGIV uses Provides expert advice to the FDA, resulting in a revised IGIV clinical trial policy that is patient friendly and less invasive

## 2001 LeBien Visiting Professor Schedule

The LeBien Visiting Professor Program, sponsored by FFF Enterprises, is designed to foster improved knowledge about the diagnosis and treatment of patients with primary immunodeficiency diseases. The program takes the form of Grand Rounds and Clinical Presentations at leading medical institutions across the country.

<b>March 2, 2001</b>	University of Nevada, Las Vegas, NV <b>Richard Hong, MD</b>
<b>May 25, 2001</b>	Children's Hospital of Wisconsin, Milwaukee, WI <b>Rebecca Buckley, MD</b>
<b>April 3, 2001</b>	Milton S. Hershey Medical Center, Hershey, PA <b>Mary Ellen Conley, MD</b>

To attend a Visiting Professor Program, please call Tamara Brown, Medical Programs Coordinator for IDF at (800) 296-4433.

## Calling for Scholarship Applications

IDF is pleased to announce the annual IDF/Novartis Scholarship campaign. Scholarship applications will be accepted from undergraduate college students diagnosed with a primary immune deficiency disease. If you are interested, or know someone who would benefit, please call our national office at (800) 296-4433 or email to [tb@primaryimmune.org](mailto:tb@primaryimmune.org) to request an application. The deadline date for scholarship request submissions is March 31, 2001.

## IDF Annual Research Grant

IDF is pleased to report that we have received 20 exceptional research grant proposals for the \$100,000, two-year Research Grant for FY2001/2002. IDF has been soliciting proposals focusing on primary immunodeficiency diseases since June 2000. Presently, the IDF Medical Review Committee is reviewing all of the proposals and will make a decision in February 2001. IDF extends a gracious thank you to all applicants who submitted proposals.

## 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</i> <i>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</i> <i>Bartow</i>	Lynne Szott Gail Moore
<b>Illinois</b>	<i>Aurora</i>	Lisa Verachtert
<b>Indiana</b>	<i>Indianapolis</i>	Rita Meldrum
<b>Iowa</b>	<i>Oxford</i>	Cindy Hora
<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>Rio Rancho</i>	Janet Dokouzian
<b>Ohio</b>	<i>Solon</i>	Judy Ranallo
<b>Oklahoma</b>	<i>Skiatook</i>	Tamie Bushyhead
<b>Pennsylvania</b>	<i>Newtown</i> <i>Indiana</i>	Terry Halper Judy Lunchuck
<b>Texas</b>	<i>Woodlands</i> <i>Lubbock</i> <i>Plano</i>	Kathy Crews John Robison Nancy Sherrard
<b>Washington</b>	<i>Kent</i>	Kris McFalls
<b>West Virginia</b>	<i>Morgantown</i>	Lisa Ray

Change of Address Requested

IDF SUSTAINING CONTRIBUTORS

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