

# IDF ADVOCATE

THE NATIONAL NEWSLETTER OF THE IMMUNE DEFICIENCY FOUNDATION



PAGE 1

Help is a phone call away



PAGE 5

New IDF Genetic Services program



PAGE 5

Dr. Sasahara wins IDF research fellowship for WAS studies



PAGE 6

How to appeal insurance denials



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## IDF's Support Network: Neighbors Who Understand and Can Help



### A CONTINUING SERIES ON IDF CORE SERVICES

In this issue of the *IDF Advocate*, we present a fourth article that focuses on IDF's Core Services Programs and how they improve the health and quality of life of people with primary immune deficiencies. This article describes the IDF Support Network and the compassionate concern, helpful information, and sense of community it provides for patients and their families across the country.

### No one should face these diseases alone

People with primary immune deficiency diseases know this scenario all too well: After struggling alone, probably for years, you obtain an accurate diagnosis for your condition. While it's a great relief to know what's wrong, and to know there is a treatment that will help, day to day you are still alone. As Kathy Antilla, an IDF local coordinator in Minnesota, describes it, "Even when you know what's wrong, you need someone to talk to where you live. You need someone to run general questions by, such as, 'What's the first infusion like?' and 'How will I know if it's working?' and 'How do I manage my life now?' You need someone who can tell you the basics from personal experience, and share how you feel. No one should have to face these diseases alone."

That's why the IDF Support Network exists: to provide compassionate support and useful information, whenever you need it, from people who have first-hand knowledge of these diseases.

## A MESSAGE FROM THE EDITOR

The IDF Support Network, described in this issue, may be the best known service offered by the Foundation. We encourage you to take advantage of it! The IDF Support Network can provide you not only with valuable information, but also with a concerned friend who understands the challenges you face. To access the Network, call us on our toll-free IDF Hotline, at **800-296-4433**. Or, if you have Internet access, come to the IDF website at **www.primaryimmune.org**. IDF will then match you with a volunteer peer contact in your community.



## IDF ADVOCATE

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## A national network

At present the IDF Support Network involves more than 80 volunteers in more than 30 states across the country. The volunteers fall into three categories: local coordinators, who help organize meetings and activities; peer contacts, who respond to calls from the field; and "action group" members, who participate in selected IDF activities. The IDF office provides resources and training to the volunteers, assists in coordinating local events, and refers calls to appropriate peer contacts.

Jennifer Scharpf, Vice President of Patient Services, who manages the IDF Support Network, stresses the importance of volunteers. "The Immune Deficiency Foundation is a national organization," she explains. "We rely on volunteers in the Support Network to ensure that IDF's mission is carried throughout the country, and that all individuals have the opportunity for peer support and educational programs. The volunteers provide invaluable support to newly diagnosed patients and their families, increase awareness of primary immune deficiency diseases, and coordinate educational seminars in their communities. IDF hosts over 20 local educational meetings annually and refers patients to peer contacts on a daily basis—this would not be



IDF Family Retreat participants

possible without the dedicated volunteers in the IDF Support Network."

Volunteers also participate in action groups. For people who want to help IDF, but cannot devote the time required to serve as a peer contact, action groups are a great way to get involved. Action groups help influence public policy, improve reimbursement of IGIV treatments and increase public awareness of pertinent issues. Most recently, over 40 volunteers assisted IDF in a local media campaign in support of IDF's Smallpox Vaccination Awareness Program. According to Ms. Scharpf, "As a result of this hard-working action group, numerous local news stories addressed the risks posed by smallpox vaccination to immune-compromised individuals."

## "BOND. DAVE BOND."

When David Bond, an IGIV product manager for the Baxter Healthcare Corporation, participates in IDF Family Retreats, he has two missions. As a representative of Baxter, a Core Services Sponsor, he is there to support the patients and learn more about their lives and needs. And as the father of two children,

he takes great satisfaction in acting as a retreat "camp counselor."

"I work with the kids while the parents go from seminar to seminar," Mr. Bond explains. "So I see firsthand the use to which IGIV is put. And the fact is, I never know which kids have a disease and which don't. If they use IGIV, they

stay healthy, they look and sound like every other kid. What could be better?"

One additional benefit of working with the children is the chance to assume the identity of a well-known film character. "Yes, the kids like to call me '007' because of my name. It's just another way we have fun and get to know each other."



IDF Family Retreat in Florida

## FAMILY RETREATS: TWO DAYS OF LEARNING, SHARING, AND FUN

### FRIDAY AFTERNOON

Families arrive at the selected resort and share their stories in a “getting to know you” seminar. Children go off in their own groups, have a scavenger hunt or other activity, and get back together with their families for a closing event.

### SATURDAY

Adults and parents join in seminars with nationally-known specialists, while children participate in fun-filled and educational activities. Seminar topics include basic concepts in immunology and genetics, IGIV manufacturing and safety, coping with chronic illness, insurance reimbursement, and school and employment issues. Families reunite for meals, and there is a “big event” at night.

### SUNDAY MORNING

One or two more seminars are held, followed by a question-and-answer session with the panel of doctors.

## Taking your call

What happens when you call the IDF Hotline? If you are calling for the first time, IDF will take your contact information, send you educational materials, such as the *Patient and Family Handbook*, and offer to connect you with a local peer contact.

The local peer contact will provide one-on-one assistance—listen to your questions and concerns, point out local educational and community resources, and help you deal with the challenges of chronic illness. States Bonnie Lee Fortlage, a nurse with a primary immune deficiency, “I was totally isolated here in

## IDF CHAMPIONS CIRCLE OF SUPPORT

### 2003 CORE SERVICES

**Services to Individuals and Families**  
 IDF Hotline  
 Patient Advocacy  
 IDF Support Network  
 Patient Notification System  
 Scholarship Program

### Public Policy

Blood Safety and Availability  
 Access to Quality Health Care  
 Support for Publicly Funded Research

### Medical and Scientific Programs

Consulting Immunologist Program  
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 IDF Research Grant Program  
 Visiting Professor Program

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North Dakota—homebound, with no access to information, no one to talk to. When I contacted IDF, they sent the handbook, and it was like the Bible for me. Then Kathy Antilla called me from Minnesota. We spoke for an hour. She knew exactly what I was talking about. Now I'm not isolated any more. I can reach a friendly and knowledgeable voice whenever I need to."

## Building community: Family retreats

In addition to providing peer contact services, the IDF Support Network helps IDF plan special events that provide educational and community building experiences for people with primary immune deficiencies and their families.

One of the most visible of these is the IDF Family Retreats Program, the brainchild of Gail Moore, an IDF local coordinator in Florida. Family retreats bring together patients, families, caregivers, health professionals, and IGIV industry representatives for two days of seminars, informal discussion, and social activities. "Because of my own difficulties getting information and dealing with these diseases years ago," relates Ms. Moore, "I decided to find a way to help others. IDF retreats let families spend time



Children's educational session

with other families who understand, and with physicians experienced in these diseases. We learn, share insights and practical approaches, and realize that it's not the end of the world to have an immune deficiency."

The doctors and other professionals who speak at the seminars donate their time, as do the corporate representatives who work with the children as "camp counselors" while their parents learn more about primary immune deficiencies. Thanks to the generous support of the IDF Core Service Sponsors, families

receive lodging, meals, and educational programming for two days for a nominal registration fee. IDF also offers scholarships to help families defray these costs. Notes Gail Moore, "We've never turned anyone away."

## How you can help

The Champions Circle of Support (see inset page 3) is a group of companies committed to assisting IDF in accomplishing its Core Services. Not only do these companies fund the IDF Support Network through their Core Services Grants, they also fund IDF Family Retreats through a separate donation.

What can you do to ensure that these important services continue? People with primary immune deficiencies and their families can further the cause of local support by volunteering to participate in the IDF Support Network and join in local meetings and activities. If you would like to get connected with a peer contact in your area, please call IDF at 800-296-4433.

## FAMILY RETREATS: A PHYSICIAN'S PERSPECTIVE

Stephen Miles, M.D., an immunologist and member of IDF's Medical Advisory Committee, spoke at an IDF retreat in Michigan at the invitation of local coordinator Debbie Arnold. Dr. Miles sees retreats as "therapeutic for patients," not only because they provide opportunities to hear and speak with physicians. "It's equally useful for patients to speak with other patients," Dr. Miles explains. "For example, for a newly diagnosed patient or a patient about to have his first treatment, speaking with someone who's been through it already is very helpful. The experienced patient will explain that, rather than starting with a low dosage, or trying out different doses, the newly diagnosed patient might see an immunologist from the start, saving time and avoiding infections and complications. That's a real advantage."

# UPDATE:

## Smallpox Vaccinations and Primary Immune Deficiency Diseases

In January 2003, the U.S. Centers for Disease Control and Prevention initiated the first phase of a national Smallpox Vaccination Program. It is estimated that 500,000 physicians, nurses, and public health workers around the country will receive the smallpox vaccination in the first phase.

In the absence of a smallpox outbreak, people with weakened immune systems due to primary immune deficiency diseases, or their close contacts should not receive the smallpox vaccine. IDF launched a national awareness campaign to educate individuals affected by primary immune deficiency diseases, health care workers, and the general public of the risks posed to immune compro-

mised individuals by the vaccine. As a result of this campaign and IDF's advocacy efforts over the past year:

- IDF was appointed as a Liaison Member of the Institute of Medicine's Committee on the Smallpox Vaccination Program Implementation.
- CDC amended their pre vaccination educational materials and screening documents to include the term "primary immune deficiency disorders."
- Numerous media stories featured messages related to the smallpox vaccine, primary immune deficiency diseases and IDF's position on the Vaccination Program.

IDF will continue its awareness campaign and keep you informed throughout all phases of the Smallpox Vaccination Program. To learn more about the smallpox vaccine and IDF's awareness campaign, call IDF at 800-296-4433 or visit [www.primaryimmune.org](http://www.primaryimmune.org).



## Yoji Sasahara, M.D., Ph.D. Awarded Fellowship for Research on Wiskott- Aldrich Syndrome

The Immune Deficiency Foundation's Fellowship Program is a national, peer-reviewed competition for clinical researchers. The program encourages the training of future specialists to accelerate medical research to improve the understanding and treatment of primary immune deficiency diseases.

The 2003 Fellowship has been awarded to Yoji Sasahara, M.D., Ph.D., Research Fellow in the Division of Immunology at Children's Hospital in Boston, Massachusetts. His fellowship research is titled, "The Role of WASP Interacting Protein in Wiskott-Aldrich Syndrome." These studies will help to establish a molecular basis of genotype-phenotype correlation in classical Wiskott-Aldrich Syndrome (WAS), understand the spectrum of immunologic defects observed in WAS patients, and identify the molecular pathology of novel WAS-like diseases.

Dr. Sasahara obtained his M.D. and Ph.D. degrees from Tohoku University School of Medicine in Sendai, Japan. Upon completion of his pediatric residency at the Hachinohe City Hospital, he was appointed as a pediatrician at the Tohoku University School of Medicine. In 2000, Dr. Sasahara was appointed a Research Fellow in the Division of Immunology, Children's Hospital Boston under the mentorship of Professor Raif S. Geha. Dr. Sasahara's research interests include the molecular pathogenesis of primary immune deficiency syndromes and therapeutic approaches for Wiskott-Aldrich Syndrome and Severe Combined Immune Deficiency.

## New IDF Genetic Services

Primary immune deficiency disorders are caused by inborn defects in the cells and tissues of the immune system. Most of these disorders are "genetically determined" and therefore inherited. So, what is a "genetic" disorder? What does this mean for you and your family members? Will you pass this on to your children? Does this mean genetic testing is available for you or your family member? If so, should you have it done, and what will it tell you? What is gene therapy and is this an option for your disorder? How can you learn more about the genetic aspects of your disorder?

These are all common questions that arise when an individual learns that the disorder he or she has is "genetic." Through IDF Genetic Services, you can learn more about the genetic aspects of your disorder. IDF has a full-time, board-certified Genetic Counselor on staff who is available to answer these questions and direct you to the appropriate resources. IDF also funds the Molecular Genetic Diagnostic Laboratory at the University of Washington in Seattle, Washington. The laboratory provides genetic testing for some of the primary immune deficiency disorders, including X-Linked gammaglobulinemia, Hyper IgM syndrome and Wiskott-Aldrich Syndrome. For more information on genetic testing and other genetic aspects of primary immune deficiency disorders, go to the new Genetic Information section of the IDF website, at [www.primaryimmune.org](http://www.primaryimmune.org), or contact Melissa Schweitzer by phone at (800) 296-4433 or by e-mail at [mps@primaryimmune.org](mailto:mps@primaryimmune.org).



# Navigating the Health Insurance Appeals Process

By Terri Seargent, Healthcare Policy Specialist, Aventis Behring, King of Prussia, PA

## My insurance carrier has denied coverage for what the doctor prescribed. What can I do?

When you or a family member is denied coverage for a medical procedure or therapy that has been prescribed or requested to be prescribed by your treating physician, it can be very stressful and may even become a crisis situation. Even the best health insurance coverage can add stress when an Explanation of Benefits (EOB) is received with those dreaded words standing out on the page—“claim denied,” “not covered,” or “amount paid: 0.”

Simply stated, a “denial” means that the insurance company has decided not to pay for the procedure or therapy that your doctor has recommended. You may have already undergone the procedure or therapy, or it may be scheduled in the near future.

Don’t panic. Stay calm. Be logical. There is an appeals process you can pursue.

## Gather the necessary information

First, obtain a full copy of your policy and of the denial letter. Under the Employee Retirement and Income Security Act (ERISA), your denial letter should include a specific reason for the denial and a reference to your plan explaining the basis for the denial.

Next, get answers to the following questions:

- Is the coverage still in force?
- Have the premiums been paid? Check with your employer when it is a group policy.
- Did the coverage change? Check with the plan administrator or the human resource person at your place of work to confirm any changes in the coverage.
- Does the policy cover the procedure or therapy? Be sure to thoroughly review your current policy, highlighting all sections that pertain to the claim.
- Has the lifetime maximum been reached? Your EOB will state the amount remaining.
- Did the doctor use the proper codes when submitting the claim?

If after the above investigation everything appears to be in order, filing an appeal is a step to consider.

## Follow these six steps

The goals of the appeals process are to allow the patient to be heard and to provide any and all information needed to convince the insurance company to change its decision and provide coverage for the procedure. When submitting your appeal, keep in mind that “the best defense is often a good offense.” In other words, it is generally better to take the time to gather information and submit a well thought-out appeal packet than to hastily submit a response and miss the opportunity to educate the insurance company about your specific situation.

### Step 1: Know the rules and procedures to follow.

- Call and inform the plan’s customer service representative or benefits manager about your questions or concerns.
- Review the instructions for submitting a complaint in writing, which should be in your plan’s description of coverage and grievance process. If any of these instructions are omitted from your policy or you cannot get the complete information from your insurer, contact the state insurance commissioner’s office to get clarification on the procedure for procuring the proper instructions.
- To set your appeal in motion, write a simple letter to your insurer about denied services, as well as a statement of your intent to appeal. The letter should be sent to the person or persons issuing the denial. Retain a copy of your letter and follow up in a few days with a phone call to ensure receipt of your letter.

### Step 2: Summarize the problem or situation in writing.

- Describe the problem, and what you think the solution should be, in writing.
- Ask your treating physician to write a letter of appeal to the insurer to accompany your letter. The physician’s letter should clearly state the medical necessity of the treatment or procedure and include supporting documentation such as an article from a clinical journal.

**Step 3: Always document the sequence of events as they occur.**

- Keep written, dated, chronological notes on file from the beginning of the appeal. This should help you stay organized and can serve as a useful reference.
- Be sure to document all contacts with the managed care plan representatives. Get the name, title, and phone number of each person with whom you talk.

**Step 4: Communicate clearly, concisely, and calmly.**

- Be persistent, and remember that your goal is to get them to accept your solution.

**Step 5: Always insist on specific details—How, when, who, where, and how much.**

- If a resolution is promised to you, ask for details in writing, such as a specific date by which your grievance will be resolved. If you do not understand, ask for clarification.
- Ask whom you should contact if you do not receive acknowledgment of your appeal in writing.
- Ask when and where you will have your grievance heard and ask how long it will take for a final decision. Ask whether you can attend the meeting and whether your physician or others can accompany you.
- Remember the cardinal rule: Always write down the name, title, date, and phone number of all parties you speak with at the insurance company.

**Step 6: Be persistent if your grievance is not resolved to your satisfaction.**

- Ultimately, you may choose to seek the assistance of a third party to resolve this matter, and that may require proceeding through a board of arbitration or retaining an attorney to evaluate the matter.

Remember, you are your own best advocate!

**GIFTS IN MEMORY OF...**

- |                         |                  |
|-------------------------|------------------|
| Edgar C. Coulter        | Andrew Gagnier   |
| Dominick J. Passalacqua | Jim Thorton      |
| Wanita M. Ouellette     | Jeannine Cline   |
| Irving Sandler          | Mildred Shablott |
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| Michael Schultz         |                  |
| Mary "Mimi" Hunn        |                  |
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| James Ernst             |                  |
| Jennings Philip Miles   |                  |
| Wayne Miles             |                  |
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| Gordon Lackey           |                  |
| Andrew Harrison         |                  |
| Sheila D. Fox           |                  |

**GIFTS IN HONOR OF...**

- |   |   |
|---|---|
| Mr. and Mrs. John Harrison's 50th Wedding Anniversary   | Jacob Waugh                                       |
| Nathan O'Neill's Christening                            | Shirley Korengold's 80th Birthday                 |
| Wally Bishop's Speedy Recovery                          | The Marriage of Dana and Gil                      |
| The Wedding Guests of Susan Schrieber and Matthew Wolfe | Gail Daniels                                      |
| John Boyle  | The Matilda Bottom Family                         |
| Mark H. Austin  | Christmas Gift to the Gedroiz Family              |
| Birth of Granddaughter and Great Granddaughter Kate     | Eileen Lackey                                     |
| Mr. and Mrs. Harry Kellman's Anniversary                | Speedy Recovery and Good Health to Elana Cavalier |
| Fred and Judy Schott's Anniversary                      | Mark and Lucretia Charlson                        |
| Anna and Nicholas Mavromoustakos' Wedding               | Blaine Marder's Birthday                          |
|   | Birth of Grandson of Zachary Cole                 |

**Frances Massa Makes a Gift to IDF**

Frances Massa, a retired teacher in New Jersey, has experienced firsthand the challenges posed by primary immune deficiency diseases, and the remarkable difference the Immune Deficiency Foundation has made for people affected by them. She has decided to recognize IDF, and help other patients, by making a contribution to the Foundation through her will.

"I lived all my life in isolation," Ms. Massa relates. "No one had a name for my disease until the 1950s. Even when I was diagnosed in 1980, there was no information, it was very difficult to get treatment and insurance coverage—there was nowhere to turn." She became aware of IDF through the Internet, in the mid-1990s, and found the Foundation's work to be vitally important. "I faced a number of fundamental problems that only IDF was addressing. The IDF survey and patient handbook, for example, defined primary immune deficiency diseases for the first time: what they do, who has them, what treatments are available, which specialists are helpful. This made all the difference in my

struggles to find care, to find IGIV, to obtain reimbursement for it as a recognized treatment, to deal with my employer's ignorance about the safety of IGIV in the AIDS era. No one person and no other organization could do what IDF has done. For people with primary immune deficiencies, the world is not the same place today because of IDF's work." For information about making estate and other contributions to the Immune Deficiency Foundation, please call 800-296-4433.

**100 Holes of Golf: Year Two**



IDF President Tom Moran congratulates Nate Burdick, Director of the Middle Atlantic PGA Junior Golf Foundation (MAPGA-JGF) at the completion of the second annual "100 Holes of Golf for Charity" in 2002. The marathon event raises money for IDF and for the MAPGA-JGF.

# IDF ADVOCATE

## Mark your Calendars!

April 21-27, 2003 is Primary Immune Deficiency Awareness Week

Visit [www.primaryimmune.org](http://www.primaryimmune.org) and learn about IDF activities to promote Primary Immune Deficiency Awareness during this special week.

June 19-21, 2003 is the date of the 2nd IDF National Conference

Register today for this exciting event to learn the most recent scientific advancements, advocate for increased research funding on Capitol Hill, gain skills to manage your health care, and share experiences with others affected by primary immune deficiency diseases.

Don't miss out! Call IDF at 800-296-4433 for more information or to receive the Preliminary Program and Registration Materials.

Address service requested



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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.

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