

20 Years
of Advocacy

by the
Immune

Deficiency

Foundation:

A Celebration



Marcia Boyle, John Boyle, and their son John receive signed poster from the IDF Medical Advisory Committee in appreciation for their work

An appreciation of Marcia and John Boyle

“When they started IDF, Marcia and John Boyle were not only concerned for their son’s health, they understood that any patient-oriented organization taking on a big, complicated challenge like primary immunodeficiencies would need allies. So as they worked to help patients, they presented IDF to the medical community as a partner, an organization which could help improve care. Doctors responded favorably, and that made all the difference in the world. It conferred legitimacy, it opened doors, it eliminated potential conflicts, it gave IDF a positive and authoritative position. Marcia’s and John’s original methods were the basis for 99% of everything that followed.”

– Jerry Winkelstein, M.D.
Chairman
The IDF Medical Advisory
Committee

In gratitude

“To everyone who has done so much to make IDF the invaluable resource it has become today, I can only offer my gratitude. Patients, families, physicians and nurses, the manufacturers of life-sustaining therapies—so many people have given so generously of their care, creativity, time, knowledge, and funding. Together we have shown what determined people can do.”

Marcia L. Boyle
Founder and former Chair
The Immune Deficiency
Foundation



It's 1980...

...and though no one knows it, you have a rare, complex, and chronic medical condition, one that can result in repeated health problems, even critical illness and death. You know only that you suffer recurrent infections, even pneumonia, and find it hard to function day to day. Most doctors, including the four you've seen, are not prepared to diagnose your condition or provide a long-term prognosis. You're exhausted, frustrated, afraid, and alone. No one understands, and you don't know where to turn.

It's today...

...and your doctor has diagnosed your condition as a primary immune deficiency. Rare, complex, chronic, the condition is potentially life-threatening and in most cases has no cure. But your doctor has placed you on a regimen of intravenous immunoglobulin infusions every several weeks. If he has questions about your care, it is easier to access experts who can help. If there's a shortage of your medication, you're listed as a priority recipient. If there's a recall, there's a mechanism to notify you immediately. Your prognosis is good, you live a full and largely independent life, and you have a network of people with similar conditions who are ready to help.

The difference is the Immune Deficiency Foundation

In its 20 years of existence, the Immune Deficiency Foundation (IDF) has done much to improve the health and quality of life of people with primary immune deficiencies. In the process, IDF has grown from one family's dream to a national organization sponsoring vital patient services, medical programs, and public policy and awareness initiatives. Still, much remains to be done. We encourage you to learn more about IDF and participate in its work.

IDF is a non-profit, national patient organization with a mission to improve the understanding and treatment of primary immune deficiency diseases through research and education.

Primary immune deficiencies in brief

- ❖ *People with primary immune deficiencies—about 1 in 500 individuals in the U.S.—lack some of the basic defenses healthy people use to fight viruses and bacteria. In about 70% of clinically significant deficiencies, their immune systems do not produce sufficient immunoglobulins (substances the body uses to fight outside agents) because of genetic or metabolic defects. In other cases, other components of the immune system are lacking.*
- ❖ *As a result, people with primary immune deficiencies live at constant risk. They more easily fall prey to infections, may have recurrent health problems throughout their lives, and may develop serious, even critical, illnesses.*
- ❖ *Today, regular infusions of immunoglobulins fractionated from plasma (IGIV), and other therapies such as bone marrow transplantation, together with informed medical care, can enable most immune-deficient people to live more independent lives.*
- ❖ *Care is costly, ranging from tens to hundreds of thousands of dollars. For years, insurance companies were uninformed about primary immune deficiencies and reluctant to cover them. Today, even when many companies cover 80% of costs, the remainder is immensely burdensome to most families.*
- ❖ *On-going scientific research may improve current therapies and reveal new ones.*



Carol Anne Demaret and her son David



Kathy Crews and her son Clayton

LOCAL CHAPTER LEADERS

<i>Norman Abshear</i>	<i>CA</i>
<i>Sarah Anderson</i>	<i>KS</i>
<i>Katherine Antilla</i>	<i>MN</i>
<i>Debbie Arnold</i>	<i>MI</i>
<i>Tamie Bushyhead</i>	<i>OK</i>
<i>Kathy Crews</i>	<i>TX</i>
<i>Bonnie Doak</i>	<i>CA</i>
<i>Janet Dokouzian</i>	<i>NM</i>
<i>Terry Halper</i>	<i>PA</i>
<i>Donna and Jerry Hobson</i>	<i>NE</i>
<i>Cyndi Hora</i>	<i>IA</i>
<i>Edric Huyke</i>	<i>NV</i>
<i>Bill Kahn</i>	<i>AZ</i>
<i>Jacqueline Langley</i>	<i>IA</i>
<i>Judy Lunchuck</i>	<i>PA</i>
<i>Evelyn Maselli and Terri Lowell</i>	<i>CT</i>
<i>Kris McFalls</i>	<i>WA</i>
<i>Barbara Meade</i>	<i>MA</i>
<i>Rita Meldrum</i>	<i>IN</i>
<i>Gail Moore</i>	<i>FL</i>
<i>Gail Nelson</i>	<i>LA</i>
<i>Mike Nunke</i>	<i>TX</i>
<i>Judy Ranallo</i>	<i>OH</i>
<i>Lisa Ray</i>	<i>WV</i>
<i>John Robison</i>	<i>TX</i>
<i>Joanie Sargent</i>	<i>CO</i>
<i>Nancy Sherrard</i>	<i>TX</i>
<i>Lynne Szott</i>	<i>FL</i>
<i>Lisa Verachtert</i>	<i>IL</i>
<i>Sonia Vohnout</i>	<i>AZ</i>

Providing assistance in the IGIV shortage

In 1999, the family of Arnold and Winifred Chait faced a terrifying challenge. Their sons are life-dependent on IGIV; without it, they may be quickly overtaken by infection, become seriously ill, and require hospitalization. In October, the Chaits learned from their normal supplier that their IGIV was simply not available because of a national shortage. "You have to realize," recounts Arnold Chait, "that's like a diabetic being told there's no more insulin. We stopped our work and all our normal activities to try to locate the medications. We thought we would go crazy."

"IDF jumped in," Mr. Chait continues, "and was successful on multiple fronts. They focused the attention of the federal government on the shortage. They identified underlying problems which had led to reduced IGIV production. They worked with the FDA, industry, and doctors so that people with primary immune deficiencies would have priority access to IGIV. They developed the SafetyNet program to establish an emergency IGIV supply. They helped sponsor an IGIV recall notification system as well. The range of help they provided was extraordinary. We could count on them to have our best interests at heart and act accordingly."



IDF local program leaders meet in Orlando



IDF program leaders and industry representatives



Aaron Ashcraft presents IDF Outstanding Program Award to Florida leaders Lynn Szott and Gail Moore



Author Sara LeBien receives award for "Our Immune System"



Marcia Boyle presents IDF Volunteer Award to Donna Hobson (right)



Scholarship recipient Stephen Miles, M.D. (left) and Jerry Winkelstein, M.D.



<i>Aaron Ashcraft, Treasurer</i>	CA	<i>Philemon Greenhawk*</i>	MD
<i>Richard Barr, M.D., Chairman</i>	CA	<i>Jerry Hobson</i>	NE
<i>John Boyle, Ph.D.*</i>	MD	<i>Robert LeBien, Vice Chairman</i>	IN
<i>Kathy Crews, Secretary</i>	TX	<i>Jeffrey Ross</i>	CA
<i>Carol Ann Demaret</i>	TX	<i>Jerry Winkelstein, M.D.*</i>	MD
		<i>(Chairman, Medical Advisory Committee)</i>	
<i>Bonnie Doak</i>	CA	<i>Thomas L. Moran, President</i>	MD

**founding trustees, with Marcia Boyle, trustee emerita*



Marcia Boyle and Jeffrey Ross



Jerry Hobson



Bonnie Doak (left) and Kathy Crews



Sara and Bob LeBien



Phil Greenhawk



Aaron Ashcraft and daughter Alison Ashcraft

IDF's services for people with primary immune deficiencies

IDF produces education, awareness, and support programs for patients and families

- ❖ *Publishes and distributes patient newsletters and handbooks, some in multiple languages, for adults and children*
- ❖ *Presents conferences which help people learn about their disorders, care options, insurance, and other topics*
- ❖ *Helps individual patients with insurance issues and in obtaining access to specialists*
- ❖ *Supports 30 local programs in 22 states; where no program exists, IDF's Operation Outreach works to spur development*
- ❖ *Administers an annual scholarship to support post-secondary education for selected patients (nearly 400 to date)*
- ❖ *Provides an informative web site: www.primaryimmune.org.*

IDF helps ensure the availability and quality of IGIV

- ❖ *Provides the SafetyNet program in response to a national shortage of IGIV. Administered by Primaryimmune Services, Inc., IDF's wholly-owned subsidiary, SafetyNet helps ensure no patient goes without IGIV or is delayed in receiving it.*
- ❖ *Worked with the FDA to adopt a new protocol for clinical trials of new IGIV products, increasing the likelihood of greater IGIV availability.*
- ❖ *Joined with partners to establish the Patient Notification Program, which guarantees that notices of product recalls reach patients if problems with blood products threaten patients' health and safety.*

Timeline of IDF Achievements

December 11, 1980, IDF is founded. Marcia Boyle is first president and chairman of the Board of Trustees. The original budget of \$1,000 has grown to \$5 million in 2001.

1981
IDF creates its Medical Advisory Committee, chaired by Jerry Winkelstein, M.D.

1981
Receives a grant from the American Legion Child Welfare Fund that permits IDF to initiate its first publications: *Statement of Case: An Overview of Immune Deficiency Diseases*; *Immune Deficiency Diseases: A Guide for Nurses*; the *IDF National Newsletter*.

1982
Newsletter Issue #1. 37 issues have been printed.



1983
First annual fellowship competition: Cutter Laboratories Fellowship (now Bayer Corporation). 17 fellowships have been awarded.

1985
Chapters developed in Ohio and California. 30 local groups now established.

1985
IDF's first annual research symposium, at the annual meetings of the American Pediatric Society/Society for Pediatric Research, organized by E. Richard Stiehm, M.D., sponsored by Sandoz (now Novartis). IDF has sponsored more than 30 medical symposia.

1986
IDF initiates the Sandoz Scholarship for post-secondary education of patients with primary immune deficiency diseases. Nearly 400 scholarships have been awarded.

1987
IDF funds its first national research grant competition. Awarded to Mary Ellen Conley, M.D. for the "Genetic and Metabolic Causes of Immunodeficiency Diseases." IDF has awarded more than 12 grants, and in 2000, instituted an annual research grant competition.

1987
IDF hires its first part-time employee. In 2001, IDF has a full-time staff of 15.

1987
First edition of the *IDF PATIENT AND FAMILY HANDBOOK*, funded by Baxter Hyland. Third edition now available, also funded by Baxter Healthcare Corp.



1989
IDF's Medical Advisory Committee provides consensus statement that IGIV is the treatment of choice for most patients with primary immunodeficiency diseases requiring immunoglobulin supplementation.

1990
IDF publishes *OUR IMMUNE SYSTEM*, written by Sara LeBien, now translated into 5 languages.



1990
IDF helps organize the first international meeting of national patient support organizations for the primary immune deficiency diseases, in Oxford, England. IPOPI is created, with Bob LeBien becoming the first chairman. The seven countries originally represented have now grown to approximately 40.





Robert Good, M.D., receives IDF Achievement Award

A vital partnership with the medical community

IDF's Programs for Medical Professionals

IDF produces education and awareness programs for physicians and nurses

- ❖ Publishes and distributes newsletters and texts for physicians and nurses
- ❖ Hosts medical symposia
- ❖ Provides post-doctoral fellowships to support the training of physicians in clinical care (see inside back cover)

IDF coordinates physician support programs

- ❖ The LeBien Visiting Professor Program
- ❖ The Consulting Immunologist Program (see inside back cover)

IDF sponsors research

- ❖ Supports a Molecular/Genetic Diagnostic Laboratory
- ❖ Presents annual research grant awards for proposals focusing on primary immunodeficiency diseases (see inside back cover)
- ❖ Manages national registries that gather important clinical information on primary immune deficiency diseases so they may be better characterized and understood.

IDF will have a full-time medical director starting in 2001.

Primary immune deficiencies affect only one in 500 people in the United States. Because most community physicians and nurses never see a case, misdiagnoses and ineffective care are not unusual. "When you put yourself in the place of a community physician," states Ramsay Fuleihan, M.D., associate research scientist and co-director of allergy and immunology training at Yale University School of Medicine (and IDF research

grant recipient), "it can be baffling to come across a primary immune-deficient patient. You weren't trained to recognize these cases, and you need help. That's why the IDF Consulting Immunologist Program is so valuable."

As a volunteer in the program, Dr. Fuleihan takes calls from doctors, reviews the details of a case, suggests tests and treatment options, provides second opinions, and helps the caller refer the patient to a center with immunology capabilities as needed. The program fields dozens of calls per month. IDF also proactively works to improve physicians' knowledge and awareness of primary immune deficiencies through the LeBien Visiting Professor Program. Sponsored by IDF and FFF Enterprises, the program brings an immunology expert to a selected facility for a day, to offer Grand Rounds, see patients, lecture, and raise awareness of primary immune deficiencies.



IDF SCIENTIFIC ACHIEVEMENT AWARDS

*Dr. R. Michael Blaese 2000
Valigen
Newton, PA*

*Dr. Rebecca H. Buckley 1994
Duke University
Durham, NC*

*Dr. Mary Ellen Conley 2001
St. Jude Children's Research
Hospital
Memphis, TN*

*Dr. Max Cooper 1993
Howard Hughes Medical Institute
Birmingham, AL*

*Dr. Robert Good 1992
University of South Florida
St. Petersburg, FL*

*Dr. Richard Hong 1996
Vermont Regional Cancer Center
Burlington, VT*

*Dr. Hans D. Ochs 1998
University of Washington School
of Medicine
Seattle, WA*

*Dr. Paul Quie 1997
University of Minnesota Hospital
Minneapolis, MN*

*Dr. Fred Rosen 1993
The Center for Blood Research
Boston, MA*

*Dr. E. Richard Stiehm 1996
UCLA School of Medicine
Los Angeles, CA*



Richard Hong, M.D., receives IDF Achievement Award



Rebecca H. Buckley, M.D., receives IDF Achievement Award



Mary Ellen Conley, M.D., recipient of IDF Achievement Award, 2001



R. Michael Blaese, M.D. (left) receives IDF Achievement Award from Jerry Winkelstein, M.D.



E. Richard Stiehm, M.D. receives IDF Achievement Award



Hans D. Ochs, M.D. (left) receives IDF Achievement Award from E. Richard Stiehm, M.D.

Douglas J. Barrett, M.D.
University of Florida

R. Michael Blaese, M.D.
Valigen

Rebecca H. Buckley,
M.D.
Duke University School
of Medicine

Mary Ellen Conley, M.D.
St. Jude Children's
Research Hospital

Max Cooper, M.D.
Howard Hughes Medical
Institute

Charlotte Cunningham-
Rundles, M.D., Ph.D.
Mt. Sinai Medical Center

Erwin W. Gelfand, M.D.
National Jewish Center
for Immune/Respiratory
Medicine

Robert Good, M.D.,
Ph.D.
University of South
Florida

Richard Hong, M.D.
Vermont Regional
Cancer Center

Richard B. Johnston, Jr.,
M.D.
National Jewish Medical
and Research Center

Alexander R. Lawton,
III, M.D.
Vanderbilt University
School of Medicine

Stephen Miles, M.D.
All Seasons Allergy,
Asthma, and
Immunology Center

Hans D. Ochs, M.D.
University of
Washington School of
Medicine

Fred Rosen, M.D.
The Center for Blood
Research

Andrew Saxon, M.D.
UCLA

William T. Shearer, M.D.
Texas Children's
Hospital

E. Richard Stiehm, M.D.
UCLA School of
Medicine

John L. Sullivan, M.D.
University of
Massachusetts Medical
Center

Diane W. Wara, M.D.
UCSF Medical Center

Jerry Winkelstein, M.D.
Johns Hopkins
Children's Center

“... There is no question that bringing in experts to talk about immune deficiencies— a subject in which, at any one center, there may be very few (or no) patients recognized— is a very good way to drive home the importance of this topic... Your organization is to be commended for its approach in educating, not just the general public, but physicians as well.”

– Steven J. Wassner, M.D.
Professor of Pediatrics and
Vice Chairman for Education
The Milton S. Hershey
Medical Center, Penn State
University College of Medicine



Max Cooper, M.D. (left) and
Fred Rosen, M.D. receive IDF
Achievement Awards

The IDF Medical Advisory Committee: 20 years of guidance and growth

The IDF Medical Advisory Committee started out as a group of six doctors, all experienced in primary immune deficiencies and convinced that supporting a patient-oriented group was the best way to achieve better care. Jerry Winkelstein, M.D., a professor at the Johns Hopkins Children's Center and founding IDF trustee, is chairman of the committee, now 20 strong. “The Committee advises IDF on medical issues,” notes Dr. Winkelstein, “helping IDF prioritize its patient programs in light of limited funds. But more and more, we help IDF network and negotiate with drug companies and managed care organizations, and evaluate research funding proposals. As IDF grows, we have been able to work on projects with real long-term impact on patients' lives.”

1992
Dr. Robert Good receives IDF's first annual Scientific Achievement Award, chosen by the Medical Advisory Committee. 10 have been awarded.

1992
IDF publishes *The Clinical Presentation of the Primary Immunodeficiency Diseases: A Primer for Physicians*, funded by the American Red Cross.



1992
IDF publishes *Primary Immune Deficiency Diseases, A Guide For Nurses*, written by Marilyn Winkelstein, RN, funded by Caremark.



1994
IDF initiates its first edition of *Clinical Updates* for physicians, funded by Armour. (Now Aventis Behring)



1994
The National Institute of Allergy and Infectious Diseases (NIAID) awards IDF a contract to establish a national registry of patients with Chronic Granulomatous Disease.

1995
IDF begins a national survey of the treatment, costs and coverage of primary immune deficiency diseases, funded by Bayer Corporation.

1995
Tom Moran joins the professional staff as the President of IDF.

1997
IDF initiates *Patient 2000*, its first public policy program, funded by Bayer Corporation.

IDF plays a significant role with the CDC in changing polio vaccine protocol to benefit primary immune deficient patients.

1997
IDF initiates the LeBien Visiting Professor Program, with AAAAI providing initial funding. 38 programs conducted, reaching over 3000 physicians.

1997
IDF initiates annual funding for a Molecular/Genetic Diagnostic Laboratory.

1997
IDF spearheads a consumer coalition that results in the establishment of a Patient Notification System for users of plasma derivatives.

1997
NIAID awards IDF a contract to conduct 8 patient registries.

1997
John Boyle appointed to serve on the FDA Blood Product Advisory Committee.

1998
National IGIV Shortage: IDF creates Advisory Committee on Blood Safety and Availability, provides Congressional and FDA testimony, conducts patient and physician surveys that quantify the shortage.

1998
IDF institutes the Consulting Immunologist Program, with a grant from Centeon. (Aventis Behring).

1999
IDF creates its subsidiary, Primaryimmune Services, Inc. (PSI), and launches Safety Net, an innovative program to distribute emergency supply of IGIV to patients, through its distribution partner, FFF Enterprises.

1999
IDF expands its network of patient education and advocacy through *Operation Outreach*, funded by Aventis Behring. 6 new programs initiated, with meetings in 5 other areas laying the groundwork for new programs.

1999
FDA Panel supports IDF recommendation to revise and expedite new IGIV products.



Terry Halper, IDF Pennsylvania program leader, and Carol Anne Demaret

IDF goes to Washington

When the IGIV product he depended on was found to spread hepatitis C, Terry Halper of Pennsylvania decided to take action. With support from IDF, he began traveling to Washington to attend FDA Blood Products Advisory Committee meetings. “At that point in the early 90s,” Mr. Halper explains, “tests to detect infections in donated blood products were based on detecting antibodies to those infections. Unfortunately, there is a lag time between the start of an infection and antibody production. A test performed in that window will not detect the infection, which may be passed on to the blood recipient.” Mr. Halper spoke to the Committee about adopting new types of testing, and the importance of IGIV safety to those who depended on it. “We were someone new on the scene,” he concludes. “We showed up at the quarterly meetings to testify, and we got their attention. It was the beginning of IDF’s public policy role. Nearly a decade later, it’s a major focus of the organization.”

Making the case for Medicare reimbursement of home IGIV infusions

After years of going to the hospital to receive intravenous infusions, Gail Nelson, a nurse, patient, and leader of the IDF Louisiana program, decided she would like to try her infusions at home, where the process would take less time and trouble. She soon realized, however, that in a few years she would be eligible for Medicare, and Medicare does not reimburse for home infusions of any kind: you must be admitted to a hospital as a day patient. So she conducted her own study, comparing her home infusion costs with a friend’s hospital infusion costs, and determined that hospital infusion was three times more expensive.

With that information she worked with her congressional representative and IDF to draft a proposal under which patients with primary immune deficiencies could receive Medicare reimbursement for



IDF Louisiana program leader Gail Nelson

home infusions. So far they have succeeded in launching an official study, with results now under review by the Health Care Financing Administration. Notes Gail Nelson, "Managing long-term care for chronic problems like primary immune deficiencies presents formidable challenges. By studying these challenges, we hope to find new solutions for patients and their families."



Debbie Arnold, IDFMichigan program leader, and her son Chris, with Senator Donald Riegle, who referred to the Arnolds' case in statements concerning healthcare reform



John Edward Porter, former Chairman, Health Appropriations Subcommittee, U.S. House of Representatives, and Joanne Pease, IDF Washington State, discuss NIH research funding



Former Texas Governor Ann Richards meets with IDF Texas program members on Primary Immune Deficiency Day

IDF's public policy initiatives: A sampling

IDF participates in public discussion of primary immune deficiencies to promote policies favorable to people who have these diseases and to raise awareness of them.

- ❖ *During the IGIV shortage crisis, IDF worked to alert government agencies, bringing patients and family members to testify*
- ❖ *IDF worked with the FDA to adopt a new clinical trial protocol to speed acceptance of new IGIV products*

- ❖ *IDF worked to create a national patient registry to notify people immediately when a blood product is recalled*
- ❖ *Representatives from IDF now have voting membership on the FDA Blood Products Advisory Committee and the HHS Blood Availability and Safety Committee.*
- ❖ *IDF testifies regularly for NIH support of research in primary immune deficiencies.*

1999
IDF creates a website, www.primaryimmune.org, supported by Alpha Therapeutics.



2000
Jerry Winkelstein, M.D. is appointed to serve on the HHS Advisory Committee on Blood Safety and Availability.

2000
IDF sponsors clinical trials to bring new IGIV brands produced by Octapharma and Grupo Grifols to the U.S. market, through PSI.

2001
IDF develops protocol for 10-year surveillance program for IGIV users, sponsored by the American Red Cross.

2001
IDF launches two pilot comprehensive care centers, sponsored by Bayer Corporation.

2001
IDF holds its first National Conference

2001
Richard Barr, M.D. becomes IDF's second Chairman of the Board of Trustees.

Timeline of Selected Medical Advances in Primary Immune Deficiency Diseases

1952
Bruton's description of the first primary immune deficiency disease, x-linked agammaglobulinemia.

1954
Description of Common Variable Immune Deficiency

1957
Description of Chronic Granulomatous Disease, a phagocytic disorder

1958
Description of Severe Combined Immune Deficiency

1960
Description of a Complement Deficiency

1965
Discovery of the separate lymphoid lineages now called T and B cells. Defects in one or both of these lymphocyte pathways provide a useful basis for definition and treatment of immunodeficiency diseases.

1968
First bone marrow transplantation for SCID and Wiskott-Aldrich syndrome, which is also the first successful bone marrow transplantation for any disorder.

1972
Recognition of ADA Deficiency as the first immune deficiency with a specific molecular or genetic defect.

1973
First use of IGIV replacement for antibody deficiency in the U.S. in a clinical trial.

1974
Published the First Classification of Primary Immunodeficiency Diseases by a World Health Organization Expert Committee. This committee report has been updated every 3-5 years.

1978
First successful use of half-matched bone marrow transplant donors for treatment of Severe Combined Immune Deficiency

1987
First use of enzyme replacement in an immune deficiency disease, ADA Deficiency

1990
First application of gene therapy to ADA Deficiency, which is also the first disorder treated by gene therapy.

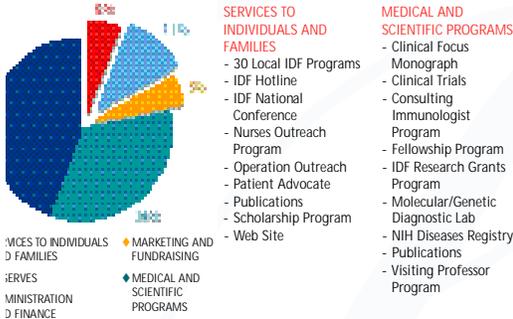
1992
The molecular genetic basis for a number of primary immune deficiency diseases discovered.

2000
Gene therapy restores immune function in x-linked SCID



Join with us.
We all have something to contribute.

IDF Revenue Spending Profile 2000



The Immune Deficiency Foundation has grown and matured in its first 20 years. But the spirit of the Foundation remains the same: with persistence, cooperation, and commitment to people with primary immune deficiencies, we can accomplish anything.

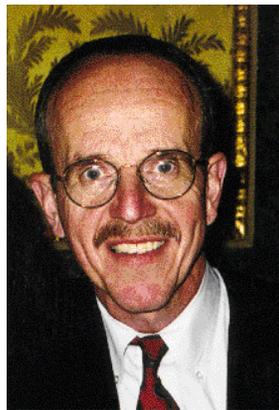
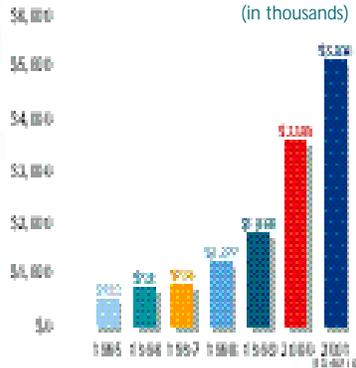
What can you do?

If you're a patient, a relative, or a friend in industry, you can join IDF, provide philanthropic support, spread word to others about the issues facing people with primary immune deficiencies, and write letters to Congress.

If you're a medical professional, you can utilize IDF's services, such as SafetyNet and the recall notification program, to help your patients. You can also participate in research and in patient registries to move care forward.

If you're a policy maker or insurer, you can listen carefully to patients and families, help find ways to improve access to care, and continue to fund research.

IDF Revenue Growth Trend (in thousands)



Richard Barr, M.D.

Introducing Richard Barr, M.D. The new Chairman of the Board of Trustees

"I am a person with a primary immune deficiency. I've experienced firsthand the fear and frustration of misdiagnoses and ineffective care, the threat of delayed or unavailable medication, and the challenges of obtaining adequate insurance. I've also experienced the intense joy and relief of finding the Immune Deficiency Foundation, of seeing new possibilities in my life, of hoping for a better future.

"I am also a physician. I understand the healthcare system from the inside, how it functions, how the various parts link. My goal is to bring both these perspectives to bear on IDF's ongoing work: to strengthen our existing patient services and develop new ones, but also to create a better healthcare environment, one in which IDF guides new research and clinical programs, strengthens its industry and government partnerships, and captures philanthropic funding for our programs and endowment. With the help of all our members, we will do even more for the short and long term needs of people with primary immune deficiencies."

For more information on ways to participate, please contact the Immune Deficiency Foundation at 800-296-4433 or www.primaryimmune.org.



IDF RESEARCH GRANT AWARDEES 2001

Scott K. Durum, Ph.D.
Laboratory of Molecular Immunoregulation
National Cancer Institute
IL-7 receptor signal transduction (related to SCID)

Sarah L. Gaffen, Ph.D.
The Research Foundation
State University of New York at Buffalo
Molecular signaling pathways used by c cytokine receptors to promote lymphocyte survival

Marianne T. Sweetser, M.D., Ph.D.
Pediatrics
University of Washington
CD40 signaling in non-X-linked hyper IgM syndrome (related to HIM)

Lloyd Mayer, M.D.
Medical Center
Mount Sinai School of Medicine
Human cytokine knock-outs: a model for intestinal disease in patients with CVID



IDF CONSULTING IMMUNOLOGISTS 2001

Rebecca H. Buckley, M.D.
Duke University School of Medicine
Durham, NC

Charlotte Cunningham-Rundles, M.D., Ph.D.
Mt. Sinai Medical Center
New York, NY

Ramsay Fuleihan, M.D.
Yale University School of Medicine
New Haven, CT

Erwin W. Gelfand, M.D.
National Jewish Center for Immune/Respiratory Medicine
Denver, CO

Robert W. Hostoffer, D.O.
Allergy and Immunology Associates
South Euclid, OH

Roger H. Kobayashi, M.D.
Allergy, Asthma and Immunology Associates
Omaha, NE

Hans D. Ochs, M.D.
University of Washington School of Medicine
Seattle, WA

E. Richard Stiehm, M.D.
UCLA School of Medicine
Los Angeles, CA

Jerry A. Winkelstein, M.D.
The Johns Hopkins University School of Medicine

IDF FELLOWSHIP RECIPIENTS (as of 12/2000)

Daniel C. Adelman, M.D. 1988
UCLA School of Medicine
Los Angeles, CA
Retinoids and interleukin-6 in common variable immunodeficiency

Emanuela Castigli, M.D. 1994
Children's Hospital
Boston, MA
CD40 knock-out mice

Laura Esswein, M.D. 1995
Washington University School of Medicine
St. Louis, MO
CD40 ligand interaction in pediatric patients with common variable immunodeficiency

Sharon Gardner, M.D. 1993
Memorial Sloan Kettering Cancer Center
New York, NY
Responses of SCID B-cells to interleukin-4

David Gossage, M.D. 1990
Duke University
Durham, NC
Adenosine deaminase deficiency: a molecular and biochemical analysis

Bodo Grimbacher, M.D. 1998
National Institutes of Health
Bethesda, MD
Hyper IgE recurrent infection syndrome: Towards identification of the disease gene(s)

Terry O. Harville, M.D. 1991
University of Florida
Gainesville, FL
Evaluation of T lymphocyte development in SCID

Donna S. Hummell, M.D. 1986
Vanderbilt University
Nashville, TN
Delineation of the regulatory derangement which is the basis of the disorder XLA

Chao Liu, M.D. 1999
Northwest Center for Medical Education, Indiana University
Gary, IN
Significance of peptidoglycan recognition in innate immunity and PID

Francis M. Lobo, M.D. 1997
Yale University School of Medicine
New Haven, CT
Regulation of CD40 ligand gene expression by cytokines, intracellular signaling pathways and transcription factors

Carolyn Lutzko, Ph.D. 2000
Children's Hospital
Los Angeles, CA
Lineage-specific expression of retroviral vectors

James Maguire, M.D. 1984
Children's Hospital Medical Center
Boston, MA
Study and description of immunoglobulin G2 deficiency states in children

Robert C. Moen, M.D. 1983
University of Wisconsin
Madison, WI
How T-cells talk to each other: the role for transplantation antigens in thymus transplantations

William J. Monafó, M.D. 1990
Washington University School of Medicine
St. Louis, MO
Elucidation of the mechanism of somatic hypermutation in immunoglobulin variable region genes

Frank Mortari, M.D. 1989
University of Alabama
Birmingham, AL
Human immunoglobulin V_H gene usage and immunodeficiency

Lynda C. Schneider, M.D. 1987
Children's Hospital
Boston, MA
T cells which involve the transmission of a signal from the surface of the cell and lead to activation of the T cell

John A. Simpson, M.D. 1985
University of Alabama
Birmingham, AL
Elucidation of the differential and maturation of human pre-B cells