SUMMER 2001 NUMBER 38

IDF ADVOCATE

THE NATIONAL NEWSLETTER OF THE IMMUNE DEFICIENCY FOUNDATION

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Everyone wants to volunteer–here's how

Bayer

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First IDF National Conference an inspirational experience

"...you walk in and realize, 'I am not alone.'"

At the back of the vast hall the last seats were going fast. As the speakers were making final preparations up front at the podium, people were still crowding in, making room, getting children settled. It was then, looking forward in the semidarkness, that you became aware of just how many people had come together here–row upon row, most meeting for the first time, many having never met *anyone* who shared their condition.

It was the opening session of the first National Conference of the Immune Deficiency Foundation, Friday morning, June 22, 2001, at the Marriott Waterfront Hotel in Baltimore. IDF President Tom Moran, new IDF Board Chairman Richard Barr, M.D., and IDF Founder Marcia Boyle stood before the crowd and tried to express the meaning of the gathering.

"This is a kind of medical Woodstock," observed Tom Moran. He gave the official count of the first gathering of people with primary immune deficiencies as over 1,000 attendees, including some 60 medical professionals and 120 representatives from industry and government. "Everyone expected a small group–but here we are!"

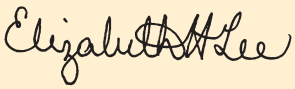
Over 1,000 people attended the IDF National Conference

Dr. Barr, himself a CVID patient, reflected on the audience's shared concerns and interests–medical, lifestyle, legislative. "In the end," he noted, "what probably matters most is the chance simply to meet more people who know what it means to have a primary immune deficiency."

FIRST CONFERENCE, CONTINUED ON PAGE 2

A MESSAGE FROM THE EDITOR

Welcome to the first issue of our revised national newsletter. We hope you will find it as helpful and informative as all the newsletters we have published to date, yet with a stronger emphasis on action, as reflected in our new title, *IDF Advocate*. The title works in two ways: we're here to act as advocates for people with primary immune deficiencies, and our readers are here to act as advocates for IDF, volunteering to join in the Foundation's work and increase awareness of it. Thanks for your support.



IDF ADVOCATE

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Carol Ann Demaret (center) with IDF friends

FIRST CONFERENCE, CONTINUED FROM PAGE 1

Marcia Boyle told the history of the Foundation, from home-grown dream to national organization. She reminded us, "Please don't take IDF for granted. It is in the interest of everyone in this room to have a strong organization for primary immune deficiency diseases. To ensure the best possible outcome in the future for yourselves and others, get involved. Go to meetings, contribute money, write letters."

Then, in what for many attendees was the emotional center of the entire conference, Carol Ann Demaret spoke about her son David, "the boy in the bubble." She noted that this remarkable child had put a face on primary immune deficiencies despite his isolation, and that she continued to feel his presence. "He never touched the world," she concluded, "but the world was touched by him." The audience members stood and applauded, together recognizing their own fears and hopes in her quiet evocation of her son's short life.

Tom Moran, IDF President, addresses the opening session. Seated, left to right, are Carol Ann Demaret, Marcia Boyle, and Richard Barr, M.D.

CONFERENCE SESSIONS ON AUDIO TAPE

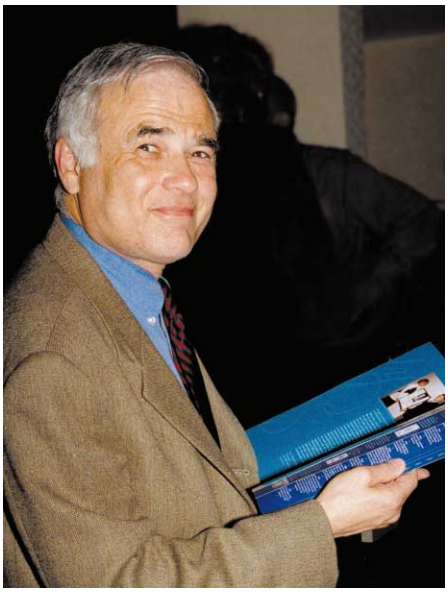
For information on ordering audio tapes of the IDF National Conference, please contact Chesapeake Audio at 410-796-0040.

So many opportunities to learn

The conference began on Thursday, June 21 with "IDF Day on Capitol Hill" (see "IDF Storms the Capitol," page 5) and a dessert reception in the evening. During Friday's scientific keynote address, IDF Medical Advisory Committee Chairman Jerry Winkelstein, M.D., a professor at the Johns Hopkins Children's Center, guided attendees through the intricacies of the human immune system, the more than 85 primary immune disorders, current therapies, and future possibilities.

For the remainder of the day, scientific sessions covered IGIV therapy, genetic testing, bone marrow transplantation, and gene therapy. These were followed by "specific diagnosis sessions" where individual conditions were discussed. The next day was filled with another full slate of sessions, addressing "living life with primary immune deficiencies" and such topics as alternative methods of IGIV delivery, health-related legislation, nutrition, parenting, and blood safety and availability.

IDF Extravaganza at the National Aquarium in Baltimore



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

Between sessions each day the halls would fill with attendees introducing themselves, comparing notes, sharing stories. At the same time, the conference's corporate sponsors and exhibitors presented information and answered questions in the exhibit hall.

So many opportunities to connect

Each evening, social events provided still more chances for people to learn and "open up." On Friday night, the National Aquarium in Baltimore was the site for an IDF Extravaganza, with an overflow party at Harrison's Pier 5 restaurant, both sponsored by Aventis Behring. On Saturday night, the IDF 20th Anniversary Celebration, sponsored by Bayer Corporation, featured cocktails, dinner, and music. IDF presented several major awards during the event. Mary Ellen Conley, M.D. of St. Jude's Research Hospital was given the 2001 Boyle Scientific Achievement Award. Then the American Legion Child Welfare Foundation, represented by Bill Pease, Executive Secretary, was given an award recognizing the original American Legion grant that provided the initial funding for IDF.

Mary Ellen Conley, M.D. receives the 2001 Boyle Scientific Achievement Award from IDF Chairman Richard Barr, M.D.

FIRST CONFERENCE, CONTINUED ON PAGE 4

AT THE CONFERENCE: PRACTICAL INFORMATION, PERSONAL FEELINGS

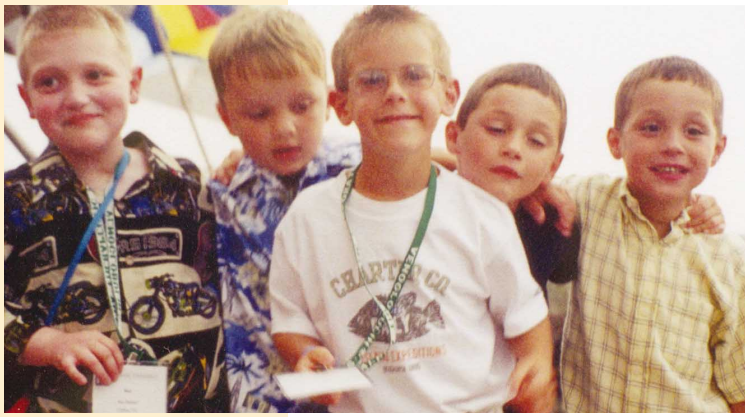
Richard Barr, M.D. (at right) and John G. Boyle (middle) present awards to IDF founders (from left) John Boyle, Ph.D., Jerry Winkelstein, M.D., and Marcia Boyle at the IDF 20th Anniversary Celebration

"Two things stand out from the conference: First, I had no idea you could infuse gammaglobulin at home. We're now looking into it. Second, seeing so many people helped us realize that we're really not alone. I don't feel as isolated as before."
– Kay Conway, attendee

Families enjoy time together at the Conference

FIRST CONFERENCE, CONTINUED FROM PAGE 3

In a moving tribute by Richard Barr, M.D. on behalf of the Board of Trustees, IDF founders Marcia Boyle, John Boyle, Ph.D. and Jerry Winkelstein, M.D. were given special awards recognizing their dedication, foresight, and perseverance for over 20 years. John G. Boyle helped present these awards to his parents and his physician. Afterward Dr. Winkelstein noted that, "I have many warm memories, having watched this large and vital organization grow over a period of two decades, from an idea first worked out on the Boyles' kitchen table. I was there at the beginning and I never anticipated how successful this would be, how many people it would help."



Boys playing at the Aquarium

A turning point

Katy Weatherford, 17, of Mountain View, California, has a primary immune deficiency. But until the IDF National Conference, only her family and her doctor knew about it. She never told any of her friends, and in fact had never met anyone else with a primary immune deficiency.

"Before, I pretty much hid my disease from my friends," Katy relates. "I didn't really want to talk about it because I thought I was a freak. But now that I've met so many other people who have similar conditions and lives, it makes it easier to talk to my friends. They are very supportive. They had no idea–it's not something that shows–but now they accept it. I've come to realize this isn't something that should be hidden. It's part of you."

Katy is thinking about studying psychology or the arts in college. In a conference session on education, she learned about laws that pertain to college education for people with immune deficiencies and other medical problems. "I think the conference was wonderful," she states. "You could learn a lot, and when you walk in and see everyone, you realize 'I am not alone.' I want to go back in two years and help other people find the help that I found."

Industry representatives at the IDF National Conference included (left to right): Kyle Bush, Baxter Healthcare; Terry Tenbrunsel, Bayer Corporation; Patrick Schmidt, FFF Enterprises; Paul Perrault, Aventis Behring; Chris Lamb, American Red Cross; and Pete DeHart, ZLB Bioplasma.

"At one of the exhibits, we were all listening to a woman talk about her young child who has common variable, and how he has horrible behavior problems on the day of treatment. The rep was very sympathetic, and it helped him understand a little about what we go through. I felt that the companies, the physicians, and the speakers really cared about us as individuals. It just seemed genuine."
– Jami Whaley, attendee

"What I heard from 80% of the attendees was that the most important aspect of the conference was the chance to talk to other people, people going through the same situations in life. We learned a lot about the outlook of the primary immune deficient patient–the isolation, the need for contact and good information, the need for more convenient and reliable medications."
– Bruce Bunyan
Aventis Behring

"People told me that just by being there and networking with others, they found a new medical resource or a new way to handle a problem, and they were just awed by the experience. Overall, we got closer to our patients, who tend to be out there at the end of a long distribution channel. This will help us in our service and support."
– Cathryn Hope
ZLB Bioplasma

IDF Storms the Capitol

"I must admit," states Kathy Antilla, IDF local program leader from Minnesota, "there's something inspiring about going to Washington and seeing the hallways and meeting rooms filled with people who care about primary immune deficiencies. I came away convinced that there was so much more we could do if we all work together."

On Thursday, June 20, 2001, as part of the IDF National Conference, buses carrying over 250 people affected by primary immune deficiencies traveled from Baltimore to the halls of Congress. In an effort led by Jason Bablak, IDF Vice President for Public Policy, they had written their House and Senate representatives to arrange brief meetings, where they would propose a national study of the safety of long-term IGIV use. Their goal: to convince their representatives to write letters to the heads of appropriations committees, asking them to fund the surveillance program. Kathy Antilla and her two sons (one a patient) met with Senator Paul Wellstone and his health aide, both of whom were eager to hear about primary immune deficiencies, very supportive of IDF's initiative, and well aware of research funding challenges.

IDF goes to Washington

"I didn't expect it to be so positive,"

IDF STORMS, CONTINUED ON PAGE 6

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IDF STORMS, CONTINUED FROM PAGE 5

Kathy states. "I expected to be listened to politely and sent on my way. But I really felt the people we met with were paying attention and were concerned."

"This was a remarkable event," notes Jason Bablak. "It was the largest Congressional effort I've ever taken part in, and the patients set it all up themselves. The group was definitely fired up by the experience."

As part of the trip, Carol Ann Demaret presented Kevin Brady, a Congressman from Texas, with the IDF Public Policy Leadership Award, citing his work as "a tireless champion in support of IDF's public policy priorities," including increased funding for research at the National Institutes of Health and support for the IGIV surveillance program. In his remarks Congressman Brady emphasized the importance members of Congress place on hearing constituents' personal experiences, and assured IDF of his continued support.

Carol Ann Demaret presents Republican Congressman Kevin Brady with the IDF Public Policy Leadership Award

The doctor is in: Jonathan Goldsmith, M.D. becomes the first IDF Medical Director

Jonathan Goldsmith, M.D. with members of the IDF Advisory Committee:
Top row, L to R: Jonathan Goldsmith, M.D., Stephen Miles, M.D., E. Richard Stiehm, M.D., Richard Johnston, Jr., M.D., R. Michael Blaese, M.D., Mary Ellen Conley, M.D., Melvin Berger, M.D.
Bottom row, L to R: Richard Hong, M.D., Jerry Winkelstein, M.D. (Chairman), Rebecca Buckley, M.D., Charlotte Cunningham-Rundles, M.D., Ph.D., Hans Ochs, M.D.

Starting August 1, 2001, Jonathan Goldsmith, M.D. became the first IDF Medical Director. Dr. Goldsmith has worked in academic medicine, where he treated people with primary immunodeficiency, and in the immunoglobulin industry, where he worked on blood safety issues.

"As full-time Medical Director," Dr. Goldsmith notes, "I can help IDF develop greater continuity in terms of day to day monitoring, guidance, and implementation to achieve medical objectives. For example, I'm eager to work with the IDF Medical Advisory Committee to obtain guidance regarding the safety of new therapies and how best to represent the Foundation's constituency–the patients–in light of these. I hope to help guide the IDF research agenda, ensure adequate supplies of therapies in the face of chronic shortages, deal with the FDA and industry to establish protocols that prove safety and effectiveness, and advance diagnosis and treatment.

"I will also bring in new perspectives by consulting with other organizations' medical directors, who work with different medical conditions but similar blood product challenges." He concludes, "There's plenty of work to do. We have a great staff in place, and I think we can make real progress."

How to become a philanthropic contributor to the Immune Deficiency Foundation

Charitable giving established the Immune Deficiency Foundation and continues to support many of its important programs on behalf of those with primary immune deficiency diseases. You can become a philanthropic contributor in the following ways:

- To make a gift of cash, mail your check to the Immune Deficiency Foundation.
- To charge a gift to MasterCard or Visa, please call IDF headquarters.
- Gifts of stock and bonds: You may make your gift in the form of appreciated securities rather than cash, in order to benefit from extra tax advantages (such as avoidance of capital gains taxes). For information, please call Marcia Boyle at IDF headquarters.
- Gifts through bequest or other forms of estate planning: You may wish to support IDF by including it in your will or trust, naming it as a beneficiary of a charitable gift annuity or charitable remainder trust, or naming it as the beneficiary of a life insurance policy. For information, please call Marcia Boyle at IDF headquarters.

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How to volunteer your help

The recent IDF National Conference inspired people as never before to assist IDF in its work. We have received a tremendous number of requests asking what types of work are needed and how to volunteer. Some of the ways you may assist us include:

- Providing personal support and information to people affected by primary immune deficiencies.
- Joining public policy letter-writing campaigns.
- Increasing public awareness of primary immune deficiencies by distributing literature or speaking in public forums.

If you have additional ideas about ways you may be of assistance, we would be happy to discuss them. For information about volunteering, please contact Jennifer Bass at IDF headquarters by calling 800-296-4433.

THANK YOU FOR YOUR GENEROUS GIFTS

The Immune Deficiency Foundation gratefully acknowledges gifts made in honor of the following:

Mark Austin
Eric Benson Blum and
Lauren Heather Kander
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Ellen Willsey 60th Birthday

The Immune Deficiency Foundation gratefully acknowledges gifts made in loving memory of the following:

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Fanny Wald
Rose Weiner

To make a gift "in honor of" or "in memory of" please send your check to the Immune Deficiency Foundation with a note indicating how you would like your gift identified.

IDF ADVOCATE

A Youth Program and childcare were provided at the IDF National Conference through a generous grant from Baxter. Highlights included a trip to Port Discovery and an Orioles baseball game (above).

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