

IDF ADVOCATE

THE NATIONAL NEWSLETTER OF THE IMMUNE DEFICIENCY FOUNDATION



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IDF Announces \$5 Million Endowment and Capital Fundraising Campaign

CAMPAIGN LAUNCH

This special issue of the *IDF Advocate* was created to announce IDF's first endowment and capital fundraising campaign. The issue is being distributed at IDF's 2003 National Conference, and also mailed to recipients across the United States along with a standard issue of the *IDF Advocate* featuring important information on IDF patient programs. Later this summer we will mail a complete campaign package that provides greater detail about the goals and structure of this special campaign; its mission to improve the health and quality of life of people with primary immune deficiencies and their families; and how to participate.

We hope you will consider participating in the endowment and capital campaign, and consider ways you can increase your participation in the IDF Annual Appeal.

A pivotal opportunity, for IDF and you

The Immune Deficiency Foundation was started twenty-three years ago, when Marcia and John Boyle decided that their young son, John G. Boyle—and the tens of thousands of other people with primary immune deficiencies—deserved better health, a better life and a strong organization that would advocate for them. Supported by annual contributions from corporations and individuals, the Foundation grew and developed its programs, improving diagnosis and treatment, expanding access to care, and increasing awareness among medical professionals, insurers, and the government. John G. Boyle grew up at the same time, learning to manage his condition with the help of his parents, physicians and the programs IDF created. He now lives a full life, which may some day include raising a family of his own.



Marcia Boyle, IDF Founder and Campaign Chairperson

The Boyles and families like them represent the "first generation" of people whom IDF has helped. Now we stand at the beginning of what will be the next generation, filled with possibility and risk. At this pivotal moment, IDF has chosen to launch its first endowment and capital fundraising campaign. With your support, the campaign will provide the Foundation—and you, the people we serve—with new strength, stability, and authority to take on the opportunities and challenges the future holds.

For Today and Future Generations: The Campaign to Endow the Immune Deficiency Foundation

The limitations of short-term funding

In one generation—approximately 20 years—the Immune Deficiency Foundation has greatly increased the likelihood that people with primary immune deficiency diseases will obtain better care and quality of life. We have become the organization that patients rely on for information, advocacy, and compassion, and that medical professionals turn to for education, training and research awards. In turn, IDF has relied on the generous annual contributions made by industry, foundations and individuals to provide support for our many programs, and to enable us to respond to crises such as the IGIV shortage.

IDF ADVOCATE

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Yet, like many national organizations of its size, IDF has found that its reliance on annual funding, and its focus on crisis response, greatly limit its ultimate capability to help those with primary immune deficiencies. Our current funding supports only annual priorities, when many of the most difficult challenges we face will require multi-year efforts. And while we always find ways to respond to emergencies, we cannot plan and execute long-term activities that might prevent those emergencies and lead to even greater gains. Thus, we must now become more forward-looking, both in terms of the funding we receive and the programs we execute.

How? We must now create a new financial basis for the Foundation, so that we have reliable funds for broad-reaching, long-term use, funds for special projects and crises, and funds for short-term, smaller-scale projects. Here is how we plan to do just that—with your help.

Building a new financial basis for IDF

Our campaign, chaired by IDF Founder Marcia Boyle, is entitled *For Today and Future Generations*. It has two components, both of which need your support if we are to be successful:

- The IDF Endowment has been established by the Board of Trustees as a large, critical fund which will produce a significant income stream. That income will enable IDF to achieve a new level of financial stability, and thus sustain concerted long-term programs in its main areas of service, including:
 - Increasing the rate of diagnosis of primary immune deficiency diseases, educating physicians on the care and management of those diseases, and supporting research and the development of new treatments

- Improving patients' access to care and quality of life
- Increasing awareness of primary immune deficiencies among medical professionals, insurers, and government policy makers.

- The IDF Capital Fund is reserved by the Board of Trustees for significant issues. It provides a designated source of unrestricted income to allow IDF the flexibility to:
 - Respond quickly to issues that could potentially threaten the patient community, such as IGIV shortages
 - React to opportunities, such as innovative research on treatments or new products that show promise.

The campaign, which is expected to last from 2003 to the end of 2008, will appeal to corporations, foundations and individuals. The campaign goal is \$5 million. At the same time, IDF hopes to greatly increase contributions to its Annual Appeal, which provides support for on-going IDF activities and immediately needed smaller-scale projects.

Strength, stability, and authority, now and in the future

What will the creation of the IDF Endowment and IDF Capital Fund mean for IDF and you?

"Success in this campaign," explains IDF Chairman G. Richard Barr, M.D., "will mean we can channel significantly more money into 'next generation' research which focuses on primary immune deficiency diseases, and move that research more quickly into the clinic. With a permanent endowment we will invest much more in supporting research than ever before. Not only will this

FOR TODAY AND FUTURE GENERATIONS

If you have contributed to the IDF Annual Appeal, we encourage you to continue to do so, and to consider making a special gift to the IDF Endowment and Capital Funds as well.

There are many ways to participate in IDF's campaign. First, you should determine your goals. For instance, you may wish to support the IDF Endowment to provide sustained monies over time that will fund longer-term programs to help the IDF community. Or you may wish to support the Capital Fund for projects that are conducted over the course of one or two years. In either case, please be assured that your support will further IDF's mission and ultimately serve individuals affected by primary immune deficiency diseases.

TYPES OF COMMITMENTS MAY INCLUDE:

- Gifts through Estate Planning
 - Life-income gifts, which return income to the donor during his or her lifetime
 - Bequests, which provide assets to IDF through your estate.
- Campaign Pledges, which provide funds to IDF for one or more years.
- Matching gifts, in which your or your spouse's employer doubles your gift to IDF.



TYPES OF FUNDING MAY INCLUDE:

- Gifts of cash (by check or credit card)
- Gifts of other assets
 - Stocks and bonds
 - Life insurance
 - IRA/retirement accounts.

IDF will be happy to work with you to arrange the right giving method for your financial situation. For more information, please contact Candace Steele or Don Weinapple at 800-296-4433 or visit us on-line at www.primaryimmune.org.



improve our understanding of primary immune deficiency diseases, it will keep researchers focused on our problems. We will hopefully be instrumental in funding research that ultimately leads to a cure for many of these diseases."

Dr. Barr continues, "Success in this campaign will mean that we can also do more to improve the patients' quality of life. We will increase our efforts to ensure earlier diagnosis of primary immune deficiency diseases, allowing appropriate treatment to begin before permanent tissue damage has begun. Our goal is also to ensure that every patient receives the best possible care in the most appropriate setting. We will also be able to expand our efforts in genetic counseling and in assisting patients in managing the burdens of insurance, education and employment."

"Success in this campaign," concludes Dr. Barr, "means that we can become an even stronger national presence, advocating more persuasively for national policies that take into consideration the needs of people with primary immune deficiencies. Success in this campaign will ensure the future of the Immune Deficiency Foundation and help us in the long run to affect the lives of many more patients and families."

With your help, we can do so much more

Participating in *For Today and Future Generations* is the best way to ensure that people with primary immune deficiencies, now and in the future, will have better health and a better quality of life. Please give careful consideration to making our campaign the focus of your charitable giving, and to joining with others in your area to encourage contributions from individuals and groups. Together, we can achieve our financial goal and develop the new programs we need.

For more information about the campaign and how to contribute, please contact the Foundation at 800-296-4433 or visit our website at www.primaryimmune.org. We look forward to speaking with you.



For Today and Future Generations

THE CAMPAIGN TO ENDOW THE IMMUNE DEFICIENCY FOUNDATION

This special issue of the *IDF Advocate* provides basic information about IDF's first endowment and capital fundraising campaign, *For Today and Future Generations*, chaired by IDF Founder Marcia Boyle. We encourage you to give serious consideration to the many benefits the campaign will enable IDF to provide, today and in the future, and to make a commitment to supporting IDF in this vital initiative.

Address service requested

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|---|--|
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| John Boyle, Ph.D.
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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.

- Alpha Therapeutic Corporation
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