Lay Organization Spotlight: Immune Deficiency Foundation

The Immune Deficiency Foundation (IDF) is the national patient organization dedicated to improving the diagnosis, treatment and quality of life of persons with primary immunodeficiency diseases (PI) through advocacy, education and research. Since 1980, IDF has provided accurate, timely information for the nearly quarter-million Americans diagnosed with PI, including patient education programs held across the country along with a wealth of publications and other resources available at www.primaryimmune.org.

For over two decades, IDF has worked with the American Academy of Allergy, Asthma & Immunology (AAAAI) and its Primary Immunodeficiency Diseases (PID) Committee to enhance the understanding of PI and treatment of patients living with this group of rare diseases. IDF and AAAAI have worked together to develop resources and influence policies that give patients access to specialists and appropriate treatments, ultimately improving patient care.

Partnership in Advocacy and Education

Through public policy action and advocacy, IDF strives to be an influential voice on issues related to PI and mobilize grassroots volunteers to take action. IDF has worked with the AAAAI PID Committee to collect valuable data to support these efforts.

When Medicare recipients with PI experienced problems getting access to intravenous immunoglobulin (IVIG), Jordan Orange, MD, PhD, FAAAAI, and the PID Committee joined with IDF to develop a survey for immunologists to quantify the issues: IDF and AAAAI Survey Regarding IVIG Treatment (2006). In the years that followed, powered by the data collected, thousands made their voices heard in Congress in support of the Medicare IVIG Access Act, allowing beneficiaries access to IVIG in the home. The bill was finally passed by Congress, and President Obama signed the Medicare IVIG Access Act into law January 10, 2013.

To understand the treatment practices of specialists, IDF worked with the PID Committee to develop and conduct a survey, the results of which were presented as an abstract at the 2007 AAAAI Annual Meeting: Specialist Perspectives on Primary Immunodeficiency Diseases: A 2006 Survey of the AAAAI Membership. IDF and the PID Committee have collaborated with other organizations to survey pediatricians (2007), family practice physicians (2009) and pulmonologists (2011), and hope to publish those results shortly. When the AAAAI created the Eight Guiding Principles for Safe, Effective and Appropriate Use of IVIG and an IVIG Toolkit, which includes recommendations for proper treatment of PI, the IDF helped in promoting these important materials. The principles and toolkit are vital resources featured on the IDF website.

As patients continued to inform IDF of insurance concerns, IDF worked with Andrew W. Murphy, MD, FAAAAI, and RADAR (Regional Advocacy Discussion and Response) volunteers to collect data on the issues from physicians: 2011 IDF & RADAR Survey of Physician Experiences with Health Insurance and IgG Therapy. RADAR consists of representatives from the AAAAI Federation of Regional, State and Local Allergy, Asthma & Immunology Societies (RSLAAIS) Assembly and American College of Allergy, Asthma & Immunology (ACAAI) House of Delegates. It works with the AAAAI, ACAA and Joint Council of Allergy, Asthma & Immunology (JCAAI) to create a network of local leaders to problem solve and serve as advocates for allergy patients and professionals.

The IDF’s Payer Policy Task Force is comprised of stakeholders, representatives of the health insurance industry and individual members of AAAAI, and this group continues to provide outreach and education to the health insurance industry.

Severe Combined Immune Deficiency (SCID) was once only identified after life-threatening infections but can now be detected using a newborn screening test. The IDF SCID Newborn Screening Campaign is an ongoing advocacy initiative supported by numerous individual members of the PID Committee, many offering testimony at the federal and state levels in support of expansion of the testing. With 16 states currently screening for SCID, IDF continues to work to get SCID added to screening panels in all 50 states.

Medical Education for Better Patient Care

IDA fosters a supportive environment for continuing medical education, promoting the recognition and management of PI among healthcare professionals. The IDF Medical Advisory Committee (MAC) and IDF Nurse Advisory Committee (NAC) are comprised of some of the world’s leading clinical immunologists and nurse clinicians. They regularly present at IDF patient education programs and contribute to IDF publications.

IDF offers resources, at no cost, for healthcare professionals:

- IDF Consulting Immunologist Program — Consults for physicians regarding patient specific questions.
- IDF and USIDNET LeBien Visiting Professor Program — Immunologists available to present at teaching hospitals.
- Clinical Focus on Primary Immunodeficiencies — Series of monographs, recently featuring Chronic Granulomatous Disease.
- IDF Guide for Nurses Immunoglobulin Therapy for Primary Immunodeficiency Diseases — 3rd Edition — Comprehensive guide developed by the IDF NAC.
- IDF Online CEU Course for Nurses: Primary Immunodeficiency Diseases and Immunoglobulin Therapy — Created
by the IDF NAC. Video series based on course available in French, German and Spanish.

- United States Immunodeficiency Network (USIDNET) — Research consortium established to advance scientific research in the field of PI, funded in part by a grant from NIAID to IDF.

For more information, visit primaryimmune.org/healthcare-professionals.

Advocacy in Practice: An Interview with Andrew W. Murphy, MD, FAAAAI

Partner, Asthma, Allergy and Clinical Immunology of Chester County
Chief, Allergy Section Chester County Hospital
Volunteer Faculty (Allergy), A. I. duPont Hospital for Children

What interested you in specializing in allergy and asthma conditions?

There were two main reasons I choose A/I as a career: the science and the philosophy of A/I care. I have always been interested in immunology. For me, it is one of the most interesting aspects of medicine. To be able to apply basic immunology knowledge clinically on a daily basis has been very rewarding.

The basic philosophy of allergy is prevention. You find out what is causing a patient’s particular allergic disease, get them well and keep them well. This concept of getting patients better and keeping them well is a treatment philosophy that resonated with me. Too much time in medicine is spent treating acute issues. There is a lot of talk about “preventive care” when in reality, medical care is acute crises care and not preventive care. Allergy is not that way.

While we certainly address acute issues, the focus of allergy care is truly preventive care. A/I physicians work diligently to get to the root cause of the patient’s disease, get them well and keep them well. We educate patient about their disease, we provide them the tools to manage their disease, and we empower patients to be active participants in their care. All of this results in our patients getting well, staying well and ultimately reducing healthcare costs. To me, A/I is the model that all of medicine should seek to emulate.

How did you get started focusing on immune deficiency?

How did it change your practice?

When I started in practice, most of my initial focus was on allergy. Over the years, I came to realize that I was an A/I physician and the “I” stood for immunology. Over the past decade or so, I slowly began to think more about primary immunodeficiency disease (PIDD) in the patients I saw.

When I talked to local physicians, I would ask them what their thoughts were on the patient who had five instances of pneumonia, or 20 ear or sinus infections. Did they really

Lay Organizations

The AAAAI places a high value on its relationships with patient advocacy organizations in support of our mutual concern for the needs of people with allergy, asthma and immunologic disease and their families. In particular, the AAAAI has an ongoing relationship with a group of organizations with whom we partner on various projects as needs and opportunities arise. We encourage you to visit these organizations’ websites for more information on their initiatives and missions.

Allergy & Asthma Network/Mothers of Asthmatics (AANMA)
www.aanma.org
www.breatherville.org

American Latex Allergy Association
www.latexallergyresources.org

American Partnership for Eosinophilic Disorders (APFED)
www.apfed.org

Asthma & Allergy Foundation of America (AAFA)
www.aaafa.org
Alaska Chapter: www.aaafaalaska.com
California Chapter: www.aaafa-ca.com
Greater Kansas City Chapter: www.aaafkc.org
Maryland/Washington DC Chapter: www.aaafa-md.org
Michigan Chapter: www.aaafamic.org
New England Chapter: www.asthmaandallergies.org
Texas Chapter: www.aaafatexas.org
St. Louis Chapter: www.aafasdl.org

Campaign Urging Research for Eosinophilic Disease (CURED)
www.curedfoundation.org

Health Research & Education (FARE)
The Food Allergy & Anaphylaxis Network (FAAN) and the Food Allergy Initiative (FAI) merged to form FARE. www.foodallergy.org

Immune Deficiency Foundation (IDF)
www.primaryimmune.org

The International Association for Food Protein Enterocolitis (IAFPE)
www.iafpe.org

The Mastocytosis Society (TMS)
www.tmsforacure.org

US Hereditary Angioedema Association (HAEA)
www.haea.org

For more information, visit primaryimmune.org/healthcare-professionals.
think this was normal? I would challenge their concept of giving the patient more and more antibiotics without thinking about why the patient needed all these courses of antibiotics. While I still see a lot of allergy patients, patients with recurrent infections are slowly being referred for a proper PIDD evaluation.

**How did you become involved with IDF?**

My initial involvement with IDF started when I was a Governor in the AAAAI Federation of Regional, State and Local Allergy, Asthma and Immunology Societies (RSLAAIS) Assembly. James M. Tracy, DO, FAAAAI, who was then Chair of the RSLAAIS, asked that I serve as liaison between the lay organizations and the RSLs. Thus began several conversations between me and Marcia Boyle. Anyone who knows Marcia knows she can be very persuasive in getting one involved in advocating for PIDD patients.

Since then, we have worked together along with others, including the Pennsylvania Asthma and Allergy Association and Pennsylvania Medical Society, to successfully address issues of patient access to Ig preparations and adding SCID screening to the newborn screening panel in Pennsylvania. I also had the pleasure of being invited by IDF to sit on their Payer Policy Task Force to have a frank discussion with insurers, pharmacies, nurses and physicians about access to Ig and treatment of patients with PIDD in the United States.

**What is an example of how IDF has provided resources for you or your patients?**

There are a variety of ways IDF has been a resource for me and my patients. As mentioned above, IDF played an instrumental role in helping allergists in Pennsylvania preserve our ability to prescribe Ig therapy for PIDD patients as well as making SCID screening a reality in Pennsylvania. Quite literally, these actions have saved and will continue to save lives for generations to come.

I have found the IDF website an incredible resource for patient education about PIDD, for advocacy or just general medical knowledge. One of the best IDF resources for physicians is the Consulting Immunologist program. Having access to the best clinical immunologists in the country to help with your PIDD patients is invaluable.

**How has research improved treatment of patients with immune deficiency over the past 10 years?**

As an A/I clinician, there are three concepts that I think have been the most important. The first has been the development of TRECes for screening newborns for SCID. This has allowed SCID diagnosis to be made promptly in the newborn period and allow appropriate referrals to SCID treatment centers to initiate life saving treatment (Chan J and Puck JM; JACI 2005 Feb; 115(2):391-8).

Secondly, the work by Orange and colleagues (Clin Immunol 2010 Oct;137(1):21-30) that evaluated trough IgG level and its relationship to pneumonia has been very helpful. This study found that higher trough Ig levels are more protective against pneumonia. Consequently, dosing for Ig has increased thus lowering a patient’s risk of developing pneumonia.

Finally, the plethora of studies showing that weekly subcutaneous Ig is as effective as intravenous Ig has allowed PIDD patients who need replacement Ig therapy a greater measure of freedom to live their lives while at the same time treat their disease.

**Have You Claimed Your Credits from San Antonio?**

If you attended the 2013 Annual Meeting and need to claim CME/CE credits, visit annualmeeting.aaaai.org for a direct link to the credit claiming system. The deadline to claim all credits is December 31, 2013.

Any requests to claim credits after the deadline will be subject to an administrative fee. Contact cme@aaaai.org with questions.

**AAAAI to Release Second Choosing Wisely List**

The AAAAI will continue participating in the ABIM Foundation’s Choosing Wisely initiative with the release of a second Choosing Wisely list. This new list will be rolled out on February 28 at the 2014 Annual Meeting in San Diego.

The goal of Choosing Wisely is to increase conversation among physicians and patients concerning procedures and tests that have the potential to be used inappropriately. In 2012, the AAAAI was one of nine medical organizations involved in the first round of developing evidence-based recommendations to help patients and physicians start conversations and make wise choices regarding diagnosis and treatment across specialty areas.

“Releasing a second Choosing Wisely list allows the AAAAI to further extend leadership in providing best care,” said AAAAI President Linda Cox, MD, FAAAAI. “At the same time, the allergy/immunology specialty will again score visibility on a national stage while we help carry the message of right care at the right time for the right patient.”

Engaging with Choosing Wisely generates media outreach opportunities for the AAAAI to educate patients and other healthcare providers on the items featured on the list. It also provides the ability to work with Consumer Reports to create supporting materials that help explain our list items in patient-friendly language.

In the months leading up to the release of the AAAAI’s new list, members can read the AAAAI’s original list of “Five Things Physicians and Patients Should Question” by visiting the Choosing Wisely website at choosingwisely.org. The website also has a library of patient-friendly resources, including ones developed by the AAAAI and Consumer Reports related to what’s on our current “Five Things” list. Use these resources as a way to encourage education and dialogue with patients.