The International Alliance of Primary Immune Deficiency Societies

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Since the description of X-linked agammaglobulinemia in 1952, our understanding of how the immune system works, and how it can cause disease when specific elements fail to function or are overactive has grown exponentially. Mutations in over 300 genes causing inborn errors of immunity, known as primary immune disorders, are now recognised [1]. Phenotypes range from increased susceptibility to infection with a restricted or a wide range of pathogens, through autoinflammation, autoimmunity, allergy and predisposition to malignancy. Although collectively these diseases are not so rare, affecting as many as 1–2/100, for many phenotypes or genotypes, only very few patients have been described to date, and the true prevalence of primary immune disorders is not possible to estimate at this time.

Physicians, physician-scientists and scientists caring for and investigating these patients have long appreciated the value of collaboration across national borders. In Europe, the power of collaboration was realised with the foundation of the European Group for Immunodeficiencies in the

late 1970s, subsequently renamed the European Society for Immunodeficiencies (ESID) in 1994. Scientific and clinical collaborations have led to the elucidation of new genetic etiologies, new developments in treatments and the development of clinical guidelines. This effort has most recently crystallised in the European Reference Network for rare immune, autoimmune and autoinflammatory disease (ERN-RITA), of which primary immunodeficiency is an important strand, with the goal of ensuring that patients in all parts of Europe have prompt equal access to the best diagnostic and treatment facilities.

In the 1980s, the Clinical Immunology Society (CIS) was formed in North America, with similar aims to those of ESID. Similarly, in 1993, the Latin American Group for Primary Immunodeficiencies, later renamed the Latin American Society for Immunodeficiencies (LASID), was established to unify regional efforts within that context. Over the last decade, the African continent has organized its efforts to promote advancement in Clinical Immunology through the African Society for Immunodeficiencies (ASID), founded in 2008. Since their inception, all of these continental societies have recognized the peculiarities of the burden and plight of PIDs in their respective regions, including relevant disparities in the level of care within and across regions. Each organization recognizes and promotes national and regional societies within their respective continents, such as the well-established relationship between ESID and the J Project, and ASID and the A Project, and each serves as a unifying forum for continental discourse in advancing the field of PID. As such, the national and regional societies are linked to the overarching continental PID Society, and in that capacity they are in an additional way part of the global immunodeficiency community. Therefore, in their

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mission, all of the continental societies embrace international collaborations with sister PID societies globally as an innovative means of meeting its variable needs in relation to the society's threefold objectives of raising public awareness, research and promotion of evidence-based management of PIDs and thereby uplift PID patients' quality of life on the continent. In Asia and Oceania, continental organization along the lines of ESID, CIS, LASID and ASID is just beginning and there are several groups in dialogue and creating durable structures. Since there are not singular present equivalents for the four legacy PID societies in Asia or Oceania this represents work in progress with regard to inclusion and representation. The Asia Pacific Society for Immunodeficiency (APSID) was formed in 2016 and is one of several emerging groups, including the Australasian Society of Clinical Immunology and Allergy (ASCIA), South East Asia Primary Immunodeficiency network (SEAPID), Asia Pacific Association of Allergy, Asthma and Clinical Immunology (APAAACI), Asia Pacific Association of Pediatric Allergy, Respiratory and Immunology (APAPARI), and the Arab Society for Primary Immunodeficiencies, as well as the national societies, the Indian Society for Primary Immune Deficiency (ISPID) and Japanese Society for Immunodeficiency and Autoinflammatory diseases (JSIAD), that are taking steps in positive directions. Importantly, the senior members of all of these societies have been active members of the wider immunodeficiency field for many years, participating in global activities.

Given the rarity of diseases to which we are committed, the value of intercontinental collaboration, however, has long been recognised with an exchange of scientific ideas, clinical material, and even personnel, moving across continental boundaries to gain additional specialised clinical and laboratory experience. Indeed, many key publications in the field share a truly international authorship. The value of these continental societies is to provide local training for students and young doctors in the specialty, and to foster a regional perspective on immunodeficiencies. Given the growth of the continental societies and in many cases country-specific societies within these regions that are part of the broader continental dialogues, the efforts have most definitely been a success. There are numerous examples of the impact of their vibrant educational missions, which have advanced both research and clinical care.

The next evolution in this journey has been to form a global alliance of clinical immunology societies, the International Alliance of Primary Immune Deficiency Societies (IAPIDS), which by design does not have a formal administrative or leadership structure, but is instead represented by senior members from the member continental societies executive committees. In many ways as physicians, physician-scientists, and scientists, we are catching up with our nursing colleagues in the International Nursing Group for Immunodeficiencies (INGID) and indeed our patients and families who for many

years have been unified within the International Patient Organisation for Primary Immunodeficiencies (IPOPI), the Jeffrey Modell Foundation (JM Centers Network, funding for advocacy and research), and the Immune Deficiency Foundation. The role of industry in supporting these societies, by financially supporting educational activities, research fellowships and databases is also acknowledged. The IAPIDS has been several years in the planning and has represented an on-going dialogue between established continental clinical immunology societies, ASID, CIS, ESID and LASID as well as inspiration from organisations such as IUIS and WHO. APSID was included as an initial Asia continental representative, appreciating that the region is very much in evolution and the next steps for appropriate Asia and Oceania continental representation will necessitate further inclusion and expansion of the Alliance. That said, a charter reflecting shared values, aspirations, paths for collaboration and inclusion was developed and ratified at the ESID meeting in Barcelona on September 22nd 2016 (see supplementary material). Signatories included elected officers of each of the continental societies, who acted with the approval of their respective boards. The charter again specifically allows for expansion of continental society members, which clearly will be needed given the nascent organizing in Asia and Oceania. A main purpose, however, is to promote dialogue, transparency and cooperation in our field and therefore inclusion present and future is of the essence and part of the founding plan.

We believe that IAPIDS will offer immediate value to members of the individual member societies and is not intended to compete with or restrict their regional activities. The initial action plan was to have representatives of each Society participate at the other society meetings, to write a joint editorial, to identify a common journal for IAPIDS (and its member societies), the *Journal of Clinical Immunology*, and to delineate future areas of collaboration and partnership. Since the foundation of the global alliance, there has been an IAPIDS meeting at each member society meeting to date, which continues to promote global dialogue amongst societies. While each continental society has their own mandate, programs and initiatives that will be developed independently of this inter-society alliance, the goal of IAPIDS is to foster collaboration and education between the societies and promote transparency, communication and global dialogue. Participation in inter-society annual meetings and other educational events helps to promote this goal. Additionally, IAPIDS allows for better and broader accessibility to expert opinions for physicians practicing in under-served, under-resourced areas of the globe, through mutual partnership. For further specifics regarding the details of IAPIDS and its charter the following website has been created: www.theiapids.org

At the highest and most relevant level, however, the mission of IAPIDS is contained within its charter and states:

“The IAPIDS exists to advance the member professional societies in education of those engaged in the care of PID patients and promote member societies in disseminating and advancing the basic, translational and clinical science of PID and related knowledge all in the name of advancing the well-being and care of patients affected by PID and related conditions.”

In that respect, we share many values with our allied nursing and patient organisations and together we can strive for the very best for patients—in clinical medical and nursing care, diagnostics, research and treatment. The value of such a global collaboration has yet to be realised, but we can build on the work we have already done as individual societies, which already have a global vision for education, and patient care. As aligned organizations we look forward to continuing this work together and joining with other global organizations such as INGID, IPOPI, the Jeffrey Modell Foundation (JM Centers Network, funding for advocacy and research), to provide advocacy in front of governments and industry as well as advance research and education in order to create a better future for

our patients—truly immunodeficiency without borders. We all look forward to IAPIDS’ next steps and to continued increased connection as a global community.

Author Contribution The authors listed represent past-, current- and elect-Presidents of each society, apart from APSID which was formed in 2016 and only has a current President, and is represented by the secretary and treasurer. At the IAPIDS meeting during the CIS meeting in Seattle, AR Gennery volunteered to draft the dialogue into the editorial, which has been seen and approved by the boards of each society.

Compliance with Ethical Standards

Conflict of Interest The authors declare that they have no conflict of interest.

Reference

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