

## Motivation letter for Chair of ESID Inborn Errors Working Party

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Dear ESID Members,

I am writing to request your support for my application to the position of Chair of the ESID Inborn Errors Working Party (IEWP). I am enthusiastic and determined to continue the impactful work achieved by the group and have the right skills and attributes to deliver in this role.

Since attending my first IEWP meeting in 2006, I realised that this was a team of enthusiastic and highly knowledgeable professionals I wanted to be a part of, to improve the outcomes for patients with IELs and learn from colleagues around the World. The IEWP perfectly combines the scientific and clinical aspects of IELs and its standing in the field has driven real change in practice, primarily through high-quality studies possible through the dedication of our members. I have had the privilege to serve on the IEWP Scientific Committee since 2018 and through this have seen first-hand the high calibre of proposals and subsequent hard work that goes into producing data and guidelines that are accessible to the entire community and see this as one of the major contributions of our group to the field. I have personally been involved in many of these studies and writing guidelines.

My previous and current leadership experience in related international societies has given me experience directly relevant to this role, providing the necessary skills and confidence to increase IEWPs reach and network for the benefit of patients globally. My close ties with the gene therapy community, patient advocacy groups and centres outside of Europe will further enhance this. More recently I have become active in collaborative efforts to ensure patients with rare diseases can access therapies across borders. ESID and particularly the IEWP can play a major role in this effort through its registries generating reliable data, a wealth of independent expert opinion and lobbying on behalf of patients and clinicians.

If elected, I intend to:

- Continue to improve support for colleagues in training through educational events and establishing a specific IEWP juniors leadership role
- Collaborate closely with the Registry Working Party to produce registries that best serve our patients and their families, particularly in generating real world data to support access to effective therapies (eg small molecules, biologics and gene therapies)
- Further foster our highly productive interactions and collaborations with groups outside of Europe through joint studies and educational meetings
- Ensure we continue to provide high-quality, high-impact, evidence-based publications with far reaching benefits for patients and the scientific field

Thank you for considering my application,



Claire Booth