

30th June 2020

Dear ESID Board,

I would like to apply for the position of **Clinical Working Party Chairperson**.

Bio

Having trained and worked in Paediatric Immunology for the majority of my career, I moved to Adult Immunology almost 8 years ago and thus bring in-depth experience of managing Primary immunodeficiency over the whole age-range. Originally from Dublin, I trained in Paediatric Immunology at Great Ormond Street Hospital, London (GOSH) and the Hospital for Sick Children in Toronto. Since completing a PhD at University College London (UCL) in 2002, studying dendritic cell biology in Wiskott Aldrich Syndrome, I have pursued a clinical academic career. I worked at GOSH and the UCL Institute of Child Health for almost 15 years before moving to the UCL Institute of Immunology and Transplantation and the linked Adult Immunology service at the Royal Free London Hospital. I currently hold the positions of Professor of Translational Immunology at UCL and Clinical Director for Immunity at the Royal Free London Hospital (RFL).

My research group is focused on understanding the molecular mechanisms that cause PID including identifying new genetic causes of PID and developing robust laboratory assays for functional validation of genetic findings in clinical practice. I have a particular interest in clinical interpretation of genomics and have been involved in developing this at national level through chairing clinical reporting groups for the NIHR-BioResource PID project and the Genomics of Rare Immune Disorders diagnostic service and as part of the UK SCID screening Diagnostic Review Panel. Building my experience through international collaboration, I am a member of the ClinGen Immunology Clinical Domain Working Executive Committee that is working to determine the clinical relevance of genes and variants for PID and of the ESID – ERN RITA Human Phenotype Ontology (HPO) immune mediated disorders consortium which is establishing the standardized vocabulary for phenotypic abnormalities in PID.

In my clinical practice at RFL, we care for over 1500 adults with Immunodeficiency. I lead the programme for Young Adults including transition from GOSH and work closely with Professor Emma Morris to provide Immunology input for our Adult PID Haematopoietic Stem Cell Transplant (HSCT) and Gene Therapy (GT) Program, counselling adults with PID for corrective therapies and managing the long health requirements for those who have had HSCT or GT for PID in childhood. I participate in multiple national and international collaborations to improve the management of PID patients including the ERN-RITA Transition group, which I chair.

I have a strong interest in teaching and promoting professional education and have run the UCL Centre for Immunodeficiency Winter School since 2009, through which I have enjoyed meeting many PID colleagues from around the globe.

Motivation letter

When I first applied to train in Paediatric Immunology, I had no idea how things would turn out – I had never worked with a Clinical Immunologist and had only knowingly seen one patient with Primary Immunodeficiency (PID) in general paediatrics. Now more than 20 years later, I feel privileged to have worked in such a rewarding and fast-moving area of medicine and to have been part of an international cohesive and enthusiastic professional group. Major improvements in diagnosis and treatment have brought new challenges in managing PID from childhood through to adulthood, from newborn screening to use of genetic sequencing and an increasing need for long-term follow up data to inform our decision making. I believe that my experience in both paediatric and adult PID brings a specific opportunity to address the changes we face as more children with PID survive into adulthood, corrective therapies are applied across the age range and as we adapt to looking after adults with partial correction or long term sequelae. I am motivated to take this position to enable us to continue to improve the way we care for our patients.

My main areas of focus, if I am elected, will be:

1. To combine basic and clinical research and clinical expertise to provide best practice guidance and highlight areas for future research
2. To promote our professional development through a range of educational opportunities
3. To support developing the next generation of Clinical Immunologists

I will plan to achieve this through a mix of publishing guidelines and consensus statements, working with the ESID registry to commission clinical studies that address gaps in knowledge, arranging seminars focused on clinical topics and supporting exchanges between centres for professional development. My intention is that the Working Party will engage many of you to participate in these activities.

My specific aims would be:

1. To establish a program for guideline publication over the 4-year term based on gaps in the current literature, working with ERN RITA, international PID organisations, nursing colleagues through INGID and patients through IPOPI
2. To promote clinical research focused on long term outcome data for specific PID, working collaboratively with other ESID Working Parties
3. To work with the Education Working Party to trial a series of webinars that are easily accessible and focus on managing particular areas of PID with expert panel discussion
4. To work with the Juniors Working Party to involve trainees to work alongside experts in the field to prepare manuscripts, undertake clinical research and arrange seminars.

Thank you for considering my application,



Siobhán Burns

Professor of Translational Immunology

Honorary Consultant in Immunology

Clinical Director for Immunity

Chair of the CWP Application

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