

Thank you for your email and for sharing the arrangements and written submissions ahead of the forthcoming APPG session on *“Ensuring a Sustainable and Resilient Stem Cell Supply for All.”*

I write on behalf of the **Regenerative and Cellular Medicine Registry (RCMR)**. Our position is firm: the UK’s stem cell ecosystem remains **a closed structure dominated by a small circle of legacy institutions** that have failed to adapt to the demographic and cultural realities of modern Britain.

The **global ethnic majority** — including African, Asian, mixed-heritage, and diasporic communities — remains **largely invisible within both national and international donor databases**, including the **WMDA (World Marrow Donor Association)** and the **NMDP (National Marrow Donor Program)**. These communities together represent the majority of humanity, yet their genetic and cultural diversity is absent from the datasets that define global donor matching and treatment access.

This exclusion is not incidental. **Anthony Nolan, in particular, has established a near-monopoly over the UK donor registry landscape, effectively erecting institutional barriers that restrict new entrants, limit innovation, and stifle independent collaboration.** The result is a **closed shop** — one that perpetuates systemic inequity and denies culturally competent organisations the opportunity to contribute.

While NHSBT and ACLT have made efforts within their capacities, none of the existing frameworks have truly addressed the **deep cultural and ethical disconnect** that persists between donor organisations and diverse communities. There is no genuine strategy for engagement with faith-based or culturally distinct populations — Muslims, Jews, Christians of varying denominations, Hindus, and others — whose participation depends on trust, ethical clarity, and cultural resonance.

From my own experience with **NHSBT** and in my previous leadership at **Precious Cells International, which was forced out of business by the closed shop approach**, we achieved **85–90% donor conversion rates** through culturally aligned, trust-based engagement. The data clearly show that people are willing — **the system simply does not know how to reach or include them.**

The **Regenerative and Cellular Medicine Registry** exists to fill that gap. Our approach integrates **culture, ancestry, and scientific precision**, ensuring that donor programmes reflect the diversity of the human family rather than a narrow demographic subset. However, when I approached AN for assistance with HLA typing, I was asked for my CV and credentials, which was offensive due diligence is required however, the UK needs a wake-up call.

We therefore urge the APPG to:

1. **Acknowledge the systemic barriers** that limit equity, representation, and innovation within the UK donor system.
2. **Recognise the exclusion of the global ethnic majority** from UK and international donor registries (WMDA and NMDP).
3. **Establish transparent pathways** for independent registries such as RCMR to contribute data, research, and community engagement without obstruction.
4. **Review and reform the monopolistic influence** of entrenched actors — particularly Anthony Nolan — to ensure open collaboration, accountability, and fair representation.

This is not merely a technical or operational issue. It is a question of **medical justice, cultural respect, and public trust**. The communities we represent are not “hard to reach.” They have simply been kept at a distance by systems unwilling to adapt.

We look forward to engaging with the APPG Steering Group and with colleagues such as Orin and Beverley to develop a truly inclusive and resilient national model that reflects the full diversity of Britain and the world.