Powering Regenerative Medicine Propulsons la médecine régénératrice

## Insights from the Network

## Creating a Culture of Ethics in Stem Cell Regulations: A Trainee Journey

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As a Postdoctoral Fellow under Dr. Ubaka Ogbogu, my research covers topics related to the ethical, legal, and societal issues associated with regenerative medicine. More specifically, it addresses epistemic injustice in the Western hegemony of scientific knowledge and identifies what Canada may learn from how low-cost therapies are developed in the Global South. I also conduct research on the experiences of participants/patients, sponsors, and regulators in relation to therapies using a participant/patient's own stem cells in Canada.



My trainee journey has been akin to an induced pluripotent stem cell – in that the opportunities for development have been limitless. Having completed my graduate training in cognitive science, I started my postdoctoral fellowship in September 2022 as a new entrant to the stem cell field. My steep learning curve on the ethical, legal, and societal implications of regenerative medicine was eased by Dr. Ogbogu's supportive supervision and the training opportunities provided by the Stem Cell Network (SCN). SCN has invested \$148M into stem cell research in Canada since 2001. With this support, stem cell researchers have made notable advancements in breast cancer, muscle regeneration, and Type I Diabetes, among other areas. SCN's commitment to trainees is evidenced by their provision of courses, fellowships, and travel opportunities to over 6400 trainees. These training opportunities have allowed trainees to advance our knowledge and skills quickly, grow our networks, and prepare us for transitioning into the workforce.





During September 2022 – January 2023, I took advantage of the Regulatory Literacy course offered by SCN in collaboration with <u>weCANreg</u>, which familiarized me with Health Canada's regulatory frameworks as they apply to regenerative medicine. Applying and building on this knowledge has had direct benefits to my research. Most importantly, taking the Regulatory Literacy course empowered me with the tools and resources to continue my learning and research in this field.

In 2023, many opportunities arose leading up to, and during, SCN's Till & McCulloch Meetings (TMM) in Toronto. At the event, I presented a poster on a recent publication by Dr. Ogbogu and myself on patient experiences and perspectives regarding therapies using their own stem cells. In my capacity as a member of SCN's Trainee Communications Committee, I also co-hosted a session on ethical, legal, and social issues in regenerative medicine. As SCN works to identify its strategic goals for 2025-2030, I had the opportunity to act as a scribe for a strategy session for principal investigators. Following this, I was interviewed about my postdoctoral research for an upcoming feature on the Stem Cells from the Sofa speaker series. I also had the pleasure of being Junior Chair during a plenary session on the scientific and ethical challenges of AI in research and clinical care.

Having benefited from these training and professional development opportunities in a short time, I am now eager to pass the baton by supporting SCN in building the future of stem cell research in Canada. Drawing on my previous experience in mental health research, I moderated an SCN-sponsored virtual panel discussion on mental health for Grade 9 and 10 students across Canada that was hosted by <a href="Let's Talk Science">Let's Talk Science</a>. I'm also part of the organizing team for Stem Cell Talks Edmonton, an event aimed at generating excitement among high school students for stem cell research and careers.

In crowning 2023 as a year of immense growth for me with SCN, I ended the year by participating in a panel to discuss the challenges and potential solutions to access and affordability of cell and gene therapies in Canada at a Parliamentary Health Research Caucus event in Ottawa. Similar to trainees, as emerging cell and gene therapies leave the comfort of their labs to enter the real world, they are faced with barriers that threaten their



success. My panel presentation focused on the regulatory barriers that continue to pose high risks to the social impact of these therapies, particularly in the areas of intellectual property, manufacturing capacity, and patient access and affordability (Council of Canadian Academies, 2020).





I also covered key focus areas for rehabilitating our current system, including:

- 1. Reforming intellectual property regulations to encourage more open science collaborations;
- 2. Decentralizing manufacturing to be closer to the point of care and reduce the treatment burden for patients, particularly those from remote communities; and
- 3. Aligning the public funding of cell and gene therapies in jurisdictions across Canada to provide more equitable access.

SCN's investment in this risk mitigation includes culturing the next generation of stem cell researchers, including those focusing on its associated ethical, legal, and societal issues.

It is not without generous support and a tangible commitment to training that, within the span of a year, one goes from being enrolled in a Regulatory Literacy course to raising awareness of the access and affordability issues of cell and gene therapies among an audience of Parliamentarians and health leaders. I look forward to continuing to address issues at the critical intersection of science and society and encourage my fellow trainees to keep their eyes open to opportunities that challenge them and propel them into the spotlight.



