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To the T21RS Executive Committee,

I am enthusiastically applying to serve as Chair of the Science and Society Committee within the Trisomy 21 Research Society (T21RS). On a personal note, I grew up with a good friend who happened to have Down syndrome. She was one of the first to teach me that she defines who she is, not her genetic condition. Early on, I noticed the constant bias she faced. But I also realized that her Down syndrome diagnosis did not define her. My interactions with her have shaped my perspective on my research and the community I aim to aid.

Currently, I am the Associate Director of the Crnic Institute Boulder Branch (CBB) for Down syndrome at the BioFrontiers Institute, CU Boulder. In this position, I am committed and excited to develop and expand new projects in the field of Trisomy 21 research at the University of Colorado Boulder. We developed CBB as the BioFrontiers Institute's strategy to integrate new researchers into the research community addressing Trisomy 21-associated disorders. BioFrontiers is a highly collaborative research institute, and we hoped to model our Down syndrome research on the same idea. Our vision is to leverage the highly dynamic and multidisciplinary efforts of more than 20 research groups from several CU Boulder Departments and Institutes into novel discoveries that lead to innovative diagnosis and treatment of medical conditions commonly seen in the Down syndrome population. We do not wish to cure Down syndrome, but rather to improve the quality of life for individuals with T21, their families, and the broader society. We provide academic and outreach opportunities, such as our own Sie Postdoctoral Fellowship Program, an NIH-funded summer workshop on Data Science in Down syndrome (INCLUDEDS3.org), and community engagement activities.

Over the past decade, the primary focus of my laboratory has been research on Down syndrome. My lab is a computational and molecular biology lab, and we utilize a range of materials, from cell lines to data collected from humans. We focus on analyzing transcriptional alterations associated with trisomy 21. We also use machine learning and develop improved computational tools for Trisomy 21. Over the past year, my lab has made substantial progress in understanding the implications of an extra copy of chromosome 21 at the RNA level. We are also linking the genes on chromosome 21 to the medical problems common in the T21 population. Interestingly, my research has brought me back to my original perspective on Down syndrome. Individuals are individuals, regardless of whether they have Down syndrome. Everyone with Down syndrome has their own life, disposition, and medical problems, just like everyone without Down syndrome.

Because my mission is to help people with Down Syndrome overcome medical disorders, I also collaborate heavily. I offer to teach anyone researching Down syndrome computational skills, so they can access the data they are interested in. Moreover, I am aware that mis-analyzing big data, can lead to huge problems. Therefore, I am currently developing a reproducible research big data curriculum that includes portions on the ethical use of AI. I have had the privilege of collaborating with interdisciplinary teams that prioritize ethical, community-centered approaches to science. This background has given me insight into the opportunities and responsibilities we hold as a scientific society in shaping public understanding and policy.

In addition to the above activities, I have developed strong ties within the local Down syndrome community, establishing strategic partnerships with the Global Down Syndrome Foundation and the Rocky Mountain Down Syndrome Association. Both groups aim to support individuals with Trisomy 21 in achieving healthy, happy, and productive lives. Part of my mission in life is to ensure that I not only make progress in our scientific understanding of Down syndrome, but also that the knowledge researchers discover is used to improve the lives of individuals with and without Trisomy 21.

Research on Trisomy 21 is making significant gains at a pace never seen before. To ensure that this information is used appropriately, we, as researchers, must maintain continuous contact with society.

There are three ways researchers should maintain contact with society: listen, reflect, and then communicate. First, we must listen. The community we research must be involved in the decisions about what we research. Our research affects them just as much as it affects us. Therefore, they not only deserve a seat at the table, but they should be guests of honor. Without their support, this research would not be possible. Second, as researchers, we must reflect on our work. We must carefully consider the dual use of our data or knowledge. At the University of Colorado Boulder, I also serve as the coordinator for Responsible Conduct of Research. In the graduate-level class I teach, Responsible Conduct of Research (GRAD5000), I urge all researchers to consider not only the potential benefits of their results but also the potential dangers. This is particularly evident in my research on Down syndrome and the studies conducted at CBB. We must think deeply not only about how to conduct research, but also whether that research will be beneficial. Finally, as researchers, we must speak. But more than talking, we must carefully and thoughtfully communicate what our research has taught us and how it can benefit health. This is not an easy task. Most researchers didn't enter the field because they love communication. But it is essential, nonetheless.

With a longstanding commitment to promoting inclusive, evidence-based dialogue among researchers, clinicians, individuals with Down syndrome, and their families, I am well-positioned to lead this committee at a crucial and challenging time in our field.

As Chair, my vision is to build upon the committee's strong foundation by:

- Expanding partnerships with family advocacy groups and education networks
- Enhancing our digital and social media outreach with accessible science content
- Facilitating training opportunities for young researchers in data and public engagement

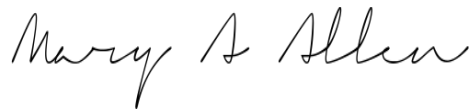
- Supporting initiatives that amplify the voices of individuals with Down syndrome in research conversations

I am deeply committed to the values and mission of T21RS and would be honored to contribute in this leadership capacity. I look forward to collaborating with fellow members to further our impact at the intersection of the academic and public dimensions.

I sincerely appreciate your time and consideration of my application.

Sincerely,

Mary A. Allen

A handwritten signature in cursive script that reads "Mary A. Allen". The signature is written in black ink and is positioned below the typed name.