

November 24, 2015

**To: NIH Translational Research Network and NIH Research Coordinating Committee
For Sexual and Gender Minorities**
From: AAN Members
Re: Statement of resignation of some AAN Members from TRN

The original invitation to join the Advocacy Advisory Network (AAN) of the NIH Translational Research Network (TRN) evoked an idealistic vision of patients and clinicians setting aside differences and working together to make life happier and healthier for people living with reproductive difference. Rejoicing at the opportunity to have a voice in major decisions about research and care that affect our community in powerful ways, representatives of multiple peer support and advocacy groups eagerly joined. AAN members include advocates with diverse lived experience, who are affected adults, parents, and children, who are affected by a variety of differences, and who range in life stage from youth to maturity. We bring skills from careers in business, academia, law, social work, conflict resolution, project management, counseling, psychology, genetics, non-profit executive directorship, and medicine. We have decades of combined experience in peer support and leadership. Additionally, for the upcoming Global DSD Update sponsored by Pediatric Endocrine Society, Arlene Baratz is co-chair of the committee on patient perspectives and peer support. Despite our representation of our community and many valuable contributions of expertise and experience since we joined AAN four years ago, we are extremely disappointed that TRN has not lived up to its initial promise.

[Alice Dreger](#) and [Tiger Devore](#) recently announced their resignations from AAN on Alice's blog. We agree with some of their ideas, and would like to clarify our own perspective. AIS-DSD Support Group, Advocates for Informed Choice, and our allies listed below are also withdrawing from AAN because of ongoing miscommunication and lack of meaningful inclusion. At this point, having our names associated with TRN is doing more harm than good because chronic issues with TRN prevent meaningful advocacy input. From its inception, despite our requests, TRN failed to include advocates in the design and goals of the project. Having been denied a presence at the initial meeting of investigators, we hoped that subsequent close involvement in projects could influence the direction of research, but most were already IRB-approved by the time we saw them. Instead of an opportunity to contribute, we have experienced a pattern of misrepresentation in which our involvement and concurrence have been falsely implied. Missed deadlines and absence of key project deliverables also frustrate us.

Let us be clear that our resignation has nothing to do with the TRN clinicians and researchers who devote their lives to caring for and about us. We deeply appreciate your presence at our support group meetings, your availability to our members, and your ability to listen and change. Outside TRN, we are delighted to be involved in ongoing projects whose design and goals reflect successful cooperative relationships. We have found we can be extremely effective in supporting the development of research that meets the needs of our communities when we are involved from the beginning in the design of research goals, when we are able to give input into sensitive language, and when we are engaged to ensure that the specific concerns of this community regarding human research ethics and informed choice are addressed. Examples of successful research we have engaged in include projects on parent experiences with making decisions about genital difference; how young women living with DSD share health information

with peers; and parent experiences with genetic testing. Currently, we are working with TRN clinicians on outside projects investigating language, how medical care is experienced, ways to deliver psychosocial care, and evidence-based best practices in CAIS. We look forward to future opportunities to work with anyone from within or outside TRN who is interested in designing research that is inclusive of community concerns.

Although clinicians may have interacted with Accord Alliance as the designated community representative, we found that indirect transmission was effectively censoring our written and verbal communications. This is disturbing because Accord Alliance was founded in 2006 by Bo Laurent (Cheryl Chase), Katrina Karkazis, Arlene Baratz, and David Sandberg to improve medical care by replacing ISNA's confrontational tactics with a fresh, collaborative approach involving multiple stakeholders. At its closure, ISNA's funds and assets were transferred to Accord Alliance, including the *Handbook for Parents* and *Guidelines for Clinicians*. Accord Alliance hosted a research and quality improvement symposium in 2009, but hasn't sponsored any non-medical events since then, according to its blog. Laurent, Karkazis, and Baratz are no longer involved. Supported in its early days by community donations, Accord Alliance's current major source of funding is the TRN grant, which in turn designates the function of DSD community representative to Accord Alliance. This suggests a major conflict of interest. Reinforcing this impression is TRN's repeated failure to share AAN opinions and concerns about various projects with TRN clinicians. For example, serious and widespread AAN concerns that a proposed photography project posed potential harm to pediatric research subjects were not conveyed accurately to clinicians. When the time came to submit that proposal, clinicians were surprised to learn our opinion. Having further misled clinicians to believe that only a minority of AAN members requested further input on the proposal, TRN circumvented its requirement for AAN support with a letter from Accord Alliance implying our approval. It was an embarrassment to all of us that the proposal was withdrawn after AAN protested the deceptive letter.

Similarly, AAN members were extensively involved for four years in writing and editing numerous drafts of educational material for a TRN family decision support tool. However, ever since we insisted recently that families be made aware of major international human rights policies involving DSD treatment, our contributions are mysteriously absent. Despite our repeated requests, a version of the decision support tool omitting human rights education is already being piloted with families. Ethics and common decency suggest that shared decision-making should include informing families that many international human rights organizations have new statements strongly affirming the right of children with diverse sex characteristics to make their own choices about irreversible interventions. The [UN High Commissioner for Human Rights](#) and the [UN Special Rapporteur on Health](#), working closely with Advocates for Informed Choice (AIC), have both endorsed these as basic human rights. DSD/intersex is increasingly prominent on an international landscape in the midst of tectonic shifts. AIC will continue to advocate for an informed consent process requiring family counseling to include discussion of both social and medical controversies. Otherwise, how will children feel later when they discover that their parents made important decisions about irreversible interventions using decision support tools that consciously excluded vital information on children's human rights? Parents have a right to know just how controversial these procedures are before they make irreversible decisions.

Finally, the original TRN grant proposal included individual letters of support from AAN member organizations. In May, we were asked to draft a new letter jointly supporting a proposal to fund

TRN for the next funding cycle. After requesting changes in the grant to provide AAN more direct involvement as a condition of support, we never saw such a letter. The grant was later submitted, leaving us to wonder if the controversy was resolved by submitting a letter from Accord Alliance without our knowledge. If so, another five years of advocate dissatisfaction and AAN misrepresentation of our constituents concerns are practically guaranteed.

AIS-DSD Support Group's mission is to foster successful stakeholder collaborations that promote community well being through peer support, informed decision-making, and advances in evidence-based care. You see our passionate commitment in the vibrant community of affected people, clinicians, and allies that we nurture. You see it at the annual continuing education meeting we sponsor in partnership with DSD teams around the country. You see it when you attend our support group meetings, hear how people experience treatment, and learn about research that matters to patients. Likewise, AIC's mission is to advocate for the legal and human rights of children born with intersex traits. Neither organization, however, can effectively support or advocate for our constituents through the AAN, and so our consciences dictate that our members must resign.

All of us see how hard you work and how much you care. We know you want to see intersex people thrive as much as we do. The world is already changing because of our mutual dedication. Together, we have the power to transform it and we look forward to further collaborations outside the TRN.

Sincerely,

Arlene B. Baratz, MD
Coordinator of Clinical and Research Affairs AIS-DSD SG
Moderator, AIS-DSD Parents Group
AIC Board of Directors and Medical Adviser

Tiger Devore, PhD
Founding member, past president and vice president, Hypospadias Epispadias Association

Amber Jones
Operations Coordinator, AIS-DSD Support Group
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Jim Lake
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