



Interstate Alliance on Stem Cell Research

Meeting Summary October 24-25, 2007 Cambridge, MA

Welcome and Introductions: Warren Wollschlager introduced Dr. Stefan Winkler with the British Consulate, thanking him for hosting the meeting. He then introduced Massachusetts State Representative Jeffrey Sanchez, and invited him to address the attendees. Following general introductions, it was noted that the meeting was open to the public, and that the public would be permitted to provide input for each of the agenda items

Grant Review Working Group: A compilation of state information from the Working Group members was discussed and participants were asked to send additional information to Marianne Horn to complete the chart. It was also suggested that additional categories be added on provisions for: (1) conflict of interest, (2) confidentiality, and (3) who is eligible for funding. It was also suggested that procedures used by federal funders (e.g., NIH) be added for comparison to the various state programs, as the NIH's procedures are very familiar to the scientific community.

Website Working Group: The draft website pages were demonstrated for the participants, who were asked to look carefully at the content and provide corrections and additions to Fran Sharples by November 21. The date of December 3 was set for the website to "go live." It was suggested that a category for other links of interest be added, and that a link to the stem cell work of the National Conference of State Legislatures be placed there. It was noted that the organization name on the website is the Interstate Alliance **on** Stem Cell Research, not **for** Stem Cell Research, as the latter title was perceived at the National Academies as connoting advocacy. The group agreed to this minor adjustment to the name to reduce that connotation of the group's purpose. They also asked that the state title be changed from "members" to "participants." Fran Sharples will also look into the possibility of changing the website address to something more easily recognizable, e.g., www.iascr.org, at the suggestion of Jonathan Auerbach.

It was agreed that all final products of IASCR should be in public domain and the website should serve as the repository. The NAS serves as the secretariat of the IASCR and will continue to maintain the website repository on behalf of the Alliance. The website working group will review future website content on behalf of the IASCR and get feedback from Warren Wollschlager and Geoff Lomax before posting.

Working Groups on “Acceptably Derived” Language and Payment Issues: The Working Group prepared a chart with 6 different models for payment policies for gamete and cell donors and participants were asked to submit information on which category their state’s policies fit into. The contents of a draft worksheet characterizing a variety of issues related to policies on cell line derivation, oversight mechanisms, consent procedures, expense and reimbursement, the permissibility of egg sharing, and access to medical care was also discussed, as well as a chart on consent rules in various states. The purpose of the chart is to pose a series of questions to help flesh out the information for the draft chart and how the policies of the various jurisdictions (states, NAS, ISSCR) fit into the picture. The group provided feedback on the draft worksheet which will be revised by the work group and then circulated to participants. Eventually, this information will be usable as the basis of an analysis of the ramifications of the various policy procedures.

Glossary Working Group: Willy Lensch distributed copies of a draft glossary of scientific terms and requested feedback. In addition, participants were asked to send the relevant portions of their state laws and regulations defining both scientific and legal terms (valuable consideration, reimbursement, compensation, etc) to Willy and Fran Sharples. Fran will separate out the legal terms and pass them on to Marianne Horn to share with the **Legal Counsel Working Group** (Marianne, Tia, Judy or Ann, Donna Levin, and Melissa).

Governance Issues: Various items were discussed about how to foster interstate collaboration. As noted above, there was nearly unanimous opinion that the group should not be “advocating” specific policies for stem cell research. Rather the IASCR should serve as a clearing-house for information about how participants have gone about developing stem cell research programs in their state or jurisdiction. Participants supported this clearing house function recognizing that non-elected state government officials cannot and do not wish to be perceived as advocating or taking a policymaking role via IASCR.

There was consensus among the participants that the alliance was operating effectively without a formal governance policy. Further, the development of such a policy could detract from the group’s productivity documenting developments in the field. There was consensus that neither elected officers nor formal voting on issues are necessary. There was a desire among the participants to continue acting by consensus.

Warren Wollschlager indicated his willingness to continue to serve a chair person for the IASCR, but expressed a desire for additional support from the participants. In response, the group requested that Geoff Lomax act as a deputy chair to the group. Subsequent to this request, CIRM endorsed this role and Geoff will assist the chair in coordinating IASCR activities. It was suggested that Warren use the title founding chair to clarify his position.

Criteria for participation were also discussed. Warren Wollschlager pointed out that the original group of participants was chosen from jurisdictions having language in law, regulation, or guidance pertaining to stem cell research and policies. In general, other states and jurisdictions are welcome to participate, but there was strong sentiment that we should not actively recruit others at this point. Rather, it was suggested that we wait until the website goes “live” and information about IASCR diffuses out, after which we anticipate contacts being made from other states. There was consensus that the unique value of IASCR is its ability to create a forum for government officials to work through policy issues. It was

therefore agreed that the core “membership” should be comprised of individuals representing state or national jurisdictions.

Report by Representatives of the International Society for Stem Cell Research: Jonathan Auerbach and Heather Rooke attended for ISSCR and familiarized IASCR with the activities and plans of the ISSCR. The planned ISSCR stem cell registry is potentially of great significance to the states as it could serve as a single source of both scientific and ethical information about stem cell lines and could facilitate cell line importation for collaboration by streamlining decisions about whether particular lines conform to state requirements. ISSCR is taking the position that they need to see the original consent forms, etc. when vetting a line and establishing the terms and conditions for derivation.

New Working Group: It was decided to establish a new Working Group on Participation of the Private Sector in Stem Cell Research. Linda Powers, Eileen Naughton, Christine Sarkisian, Milt Wallack, and Stefan Winkler agreed to be members of this new group. Their purview will include policies for intellectual property.

Long-term IASCR Funding: At the moment, IASCR is being supported by funding provided by the National Academies’ Presidents along with in kind contributions from the states and the British Consulate. The National Academies’ funding pays for various aspects of meeting expenses (travel for those without travel funds, catering, etc.) and has enabled the creation and maintenance of the IASCR website. This funding will be enough to operate on for the first year or perhaps somewhat longer. After that, it is hoped that the participating states will be in a position to pool funds to support the National Academies’ role as the Secretariat for the IASCR, but details will need to be worked out in the future. Ann Willey, Fran Sharples, Warren Wollschlager, and Dan Gincel agreed to form a new working group on Sustainability of IASCR to work on this.

Other Discussion Items

- All non-final IASCR documents are to be clearly labeled “Draft, not for public distribution. This document does not represent the views of this IASCR as an organization or of any individual.”
- A letter from John Simpson to Warren Wollschlager was distributed and discussed. It was the consensus of the group that all future meetings of the IASCR would be open to the public.
- Formation of the IASCR has generated some media attention. While all IASCR participants are encouraged to deal directly with the media, Geoff and Warren pointed out that they are referencing the mission statement in their discussions with the media.
- Participants agreed that while the goal of enhancing video conferencing capacity at the institutional level is of value, this goal will not be addressed by the IASCR.
- Next meeting: Merc Fox will send calendars out for March and April to poll participants for their availability during those months. Possible location: Washington D.C.

List of Attendees

First	Last	Affiliation
Jonathan	Auerbach	GlobalStem, Inc.
Valeria	Bogomolnaya	British Consulate
Susan	Carlson	WiCell Research Institute
Judy	Doesschate	State Department of Health (NY)
Merc	Fox	NAS
Dan	Gincel	Maryland Technology Development Corporation
Neelangi	Gunasakera	British Consulate
Marianne	Horn	Department of Public Health (CT)
William	Lensch	Children's Hospital Boston
Donna	Levin	Department of Public Health (MA)
Geoffrey	Lomax	California Institute for Regenerative Medicine
Melissa	Lopes	Department of Public Health (MA)
Dot	Mullen	Office of State Representative Eileen Naughton (RI)
Eileen	Naughton	House of Representatives (RI)
Tia	Powell	State Department of Health (NY)
Linda	Powers	Toucan Capital Corp.
Naomi	Ridge	British Consulate
Heather	Rooke	ISSCR
Noel	Roycroft	Office of State Representative Jeffrey Sánchez (MA)
Jeffrey	Sánchez	House of Representatives (MA)
Christine	Sarkisian	Canadian Consulate
Fran	Sharples	NAS
Susan	Stayn	Stanford University
Milton	Wallack	Stem Cell Research Coalition of CT
Ann	Willey	State Department of Health (NY)
Stefan	Winkler	British Consulate
Warren	Wollschlager	Department of Public Health (CT)
Jennifer	Wood	Office of Lt. Governor Elizabeth Roberts (NJ)
Eli	Zupnick	Office of Lt. Governor Elizabeth Roberts (NJ)

Contact information for individual participants may be obtained from the IASCR Secretariat at the National Academies: <<http://www.iascr.org/contact.shtml>> or [fsharples \[at\] nas.edu](mailto:fsharples@nas.edu).