International RDC/TMD Consortium Fourth Annual Meeting 3/10/04 11am-1pm Sheraton Waikiki Hotel, Honolulu Meeting minutes

All members and guests were welcomed (see attached attendance list). Of 46 current members, 2 have moved to Associate membership status, 8 did not respond to email inquiries regarding the Consortium (of which 4 non-responders had old email addresses), and approximately 17 attended the Consortium meeting, with several other Consortium members attending IADR but not able to make the Consortium meeting due to travel conflicts. Two of the new members (see below) were able to attend the meeting.

2 New member installation

- a. Mark Drangsholt presented a brief summary of each of the proposed new members.
- b. A vote was taken, and all proposed new members were approved by the 14 voting members present-unanimously, and by 7 voting members via the internet.

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- d. New members are:
 - i. Robert Celic (Zabreb, Croatia)
 - ii. Jin-Woo Chung (Seoul, South Korea)
 - iii. Sung Chang Chung (Seoul, South Korea)
 - iv. Walter Diaz (Santiago, Chile)
 - v. Dominik Ettlin (Zurich, Switzerland)
 - vi. Alan Glaros (Kansas City, Missouri, US)
 - vii. Paulo Goes (Recife, Brazil)
 - viii. Gustavo Mendonca (Taguatinga, Brazil)
 - ix. Fayez Saleh (Beirut, Lebanon)
 - x. Jose Velasco-Neri (Guadalajara, Mexico)
 - xi. Kerstin Wahlund (Linköping, Sweden).
- e. A by-laws change was discussed that would allow voting via email ballot, and to be conducted at other times in addition to the Annual Meeting. The members approved this development. A draft of the By-Laws containing this change will be submitted to the full membership via email for final approval.

3 Summary of current activities

a. Web-site: Scott McCall, at the University at Buffalo, will become the new webmaster. Ed Truelove/UW will continue to allow Department of Oral Medicine Departmental server to be used to support Consortium activities; this plan is satisfactory with the new web-master, but who may in the future decide to physically relocate the service to UB. All materials posted on the web will be in Adobe Acrobat format in order to prevent unauthorized modifications to the documents. Microsoft Word versions of posted documents will be available to Consortium members by submitting a request to the webmaster. The membership agreed that this was a reasonable plan, in order to prevent misuse of materials, and that requiring translation authors to request

- permission to use posted documents in new formats was useful in order to help maintain the appropriate integrity of Consortium documents.
- b. <u>Citations to the RDC/TMD</u>. Members agreed that citation standards on using the RDC/TMD in published research needed to be posted on the web-site; the standards should include which version of the RDC/TMD was used, explanation of which items from the RDC/TMD were used, and a statement about examiner training and reliability.

c. RDC/TMD Protocol and Translations

- i. A revised version of the specifications from the original RDC/TMD examination will be posted on the Consortium website. The revised version will include the clarification of procedures as defined by the RDC/TMD Validation Study Group and as relevant to the operations contained in the original RDC/TMD. These are mostly similar to the modifications utilized when Sam Dworkin and Kimberly Huggins conducted training via the international planning grant, along with some additional clarifications introduced by the Validation Study Group.
- ii. Update on language translations: translations and back translations have been conducted at UB/Ohrbach and UW/Dworkin and Huggins. Attached is a listing of all translations conducted to date and the status of each. We ask all translators to carefully review the information in the Table pertaining to their translation of the RDC/TMD, and notify Richard Ohrbach if there are errors or omissions.
- iii. Update on NUS software: Although Adrian Yap was unable to attend the meeting this year, he submitted a brief presentation outlining the direction for further developments in the NUS software for administering the RDC/TMD protocol. The software is being rewritten to make it user extensible for adding additional items and response options and methods, in order to allow the software to be used and configured dynamically by the end-user. Although a web version is being developed, which has the advantages of being updated in real-time and immediate access to all translated versions, the problems in human subjects protections and data cleaning, both of which require resources at present unavailable, associated with web-based immediate transfer of data make a web version difficult to implement generally. Yap has partnered with a Singapore corporation that is engaged in medical data management world-wide for assistance in this next phase of software development. The software development is occurring in conjunction with a prospective Consortium-based research proposal being developed by Richard Ohrbach and Thomas List; the content and methods issues in this proposal will contribute to the shaping of the software platform, which will be available to all Consortium members regardless of whether they participate in the proposal or not.

d. Ongoing RDC/TMD research projects: progress updates

i. An overview of the <u>RDC/TMD</u>: <u>Reliability and Validity Study</u> was presented by John Look, U of Minnesota (UM). Participating sites: UM/Eric Schiffman PI and Project PI; UB/Richard Ohrbach PI and UW/Ed Truelove PI. Look emphasized the multiple aspects of the study oriented towards validation and extension of the original RDC/TMD. He described the major domains of

- physical assessment implemented in order to test the examination and diagnostic protocols, in order for members to have a better sense of the scope of this project, allowing for parallel but non-overlapping (if desired) proposals to be developed at the present time.
- ii. Mark Drangsholt provided an overview of a study of Pain in Adolescents:

 Biologic/Psychosocial Risk Factors Study, which Linda LeResche is the PI.

 The study is both a population-based cross-sectional study of 3,101 11 to 17 year olds, and a 3 year cohort study of 1,996 11 year old children. The major aim is the identify risk factors for developing pain conditions. Data collection and initial main analyses are done for the cross-sectional study, while the cohort study data collection will be complete in the next month.
- iii. Frank Lobezzoo/ACTA (Amsterdam) briefly described a pilot validation study being conducted comparing "super" normals vs. persons with TMD vs. persons with dental pain. Provocation tests are being utilized.
- e. <u>Consortium-based proposals</u>: Richard Ohrbach summarized the current status of the proposal he and Thomas List are developing, which includes as another key site, UW/Truelove and Huggins, and 13 other sites within the Consortium. He acknowledged that the development of the proposal is slow compared to the initial hope regarding development and submission. He and the research team in attendance at IADR met separately in order to work on this proposal.

4 Administration

- a. <u>Dues collection</u>: Mark Drangsholt urged members to submit dues via check as soon as possible. There is the possibility for this Consortium becoming recognized by IADR as a section so that dues collection could be conducted via that mechanism. Funds raised via dues collection off-set the cost of paying for meeting rooms when the IADR is not held in the US and for the web site URL.
- b. Bylaws revision regarding membership categories. There is some confusion in the original by-laws regarding the differing categories of membership. The Steering Committee discussed this prior to the general meeting, but could not find ready agreement regarding a sensible alternative, and as such this issue was discussed briefly at the General meeting. This issue should be targeted for separate review by the appropriate sub-committee for further discussion and recommendations. Committees. Sam Dworkin described the committees as identified in the By-Laws, and he solicited interest in participation now that the committees can begin to function. It was suggested that individuals who are not elected officers of the Consortium serve as committee chairs. This will be implemented on an individual basis within each committee as each committee establishes itself. In addition to the four committees soliciting working members from the Consortium membership, the Steering Committee was also mentioned (which is composed of the Consortium Officers and Executive Administrator) so that members understand the full organizational structure.
 - i. Research and Publications
 - ii. Organization and Communications
 - iii. Data Collection
 - iv. Translations and Data Management
- c. <u>Symposium for 2005</u> (concurrent with IADR annual meeting) was discussed, and Mark Drangsholt volunteered to Chair this Symposium; one role of the immediate past

- president (Sam Dworkin) is to assist the symposium organizer in topic development and speaker selection.
- d. Workshop for 2005. Another idea presented for next year's IADR is to conduct a workshop for review of the RDC/TMD clinical examination, especially in light of both new un-calibrated members and the slight revisions in how some examination items are conducted. We included the idea of invited a staff member of the NIDCR to present to our group, in conjunction with the workshop, material regarding clinical trials as relevant to the establishment and development of calibrated examiners. If conducted, this workshop would be in addition to the regular Consortium meeting. It was suggested that if such a workshop were to occur that it be publicized in relevant journals.

5 New Consortium Activities

- Establish cultural equivalency of instruments. There was discussion of cultural equivalency among different languages compared to the English version, and also within the English version with different cultures within the US. Richard Ohrbach proposed to the members that a new goal for the Consortium, now that all current members have adequate translations (or are about to, given the three translations at present in final review), is to review each translation for cultural equivalency. Ohrbach presented a brief summary of recent efforts from Francisco Pereira and Paula Goes, both of Brazil, who worked collaboratively to revise the Brazilian Portuguese translation in order to make it culturally appropriate. The German group, under direction of Mike John in conjunction with a recent revision of the German translation, has approached these problems as well. A summary of guidelines will be posted on the Consortium web site so that members will have additional information regarding how to address this critical topic. Octavia Plesh asked about cultural adaptation of the English version, for other American groups, and it was similarly acknowledged that the US English language version of the RDC/TMD may require development of a parallel English-language version for use in non-White English-speaking cultures residing within the US.
- b. Recommendations from Consortium for outcomes measures for TMD research. Mike John presented a summary of recent developments by a pain research working group, as recently published in Pain, suggesting that interested Consortium members could form a committee to develop specific guidelines, along with instrument recommendations, for TMD research. Interest in this idea was expressed. One suggestion was to insure emphasis was placed also on the operationalized physical axis examination portion of the RDC/TMD protocol. Dr. John will form a working group for this project.
- c. <u>Funding possibilities for the Consortium</u>. Sam Dworkin encouraged members to review the NIH Roadmap, which describes the funding priorities and direction that NIH is currently pursuing. There have been two recent RFA (Request for Application) postings, one focused on international research planning, and the other on multicenter cohort study of incidence of chronic orofacial pain.
- 6 **Data Registry and Methodology**. Sandra Myers gave a brief description of the NIDCR-funded TMJ Implant Registry (TIRR), established at University of Minnesota (PI: Jim

- Fricton) and solicited participation of treating clinicians for referral of appropriate patients into that clinical database.
- 7 **Consortium Meeting for Next Year.** Plans discussed included presentation on multi-site US study methods by Octavia Plesh, and report on multi-site European study on TMD examination methods, by Frank Lobbezoo.
- 8 Adjournment.