

Conference call
Autism Speaks / CDC Epidemiology Subcommittee

January 2007

1. Minutes from December 2006 were approved with minor modifications.

It was agreed to create condensed minutes from past conference calls to be posted on the web site of the International Epidemiology Network so that new members can gain an understanding of the history of the subcommittee.

2. Updates from the working groups

a. Developing countries working group

Uganda: US researchers made a request for support for a visit to Uganda to explore the possibilities for conducting research in this country. Autism Speaks will consider this request.

China: A copy of a mini-proposal from a Chinese research group has been distributed to several sub-committee members for comment. The researchers have been advised to submit the proposal via one of Autism Speaks' regular funding mechanisms.

The point was raised that the subcommittee's agenda of supporting research in developing countries does not fit well into the regular Autism Speaks funding mechanisms, therefore the subcommittee may want to create new mechanisms for these kinds of studies. It was agreed this topic should be discussed in more details at the pre-IMFAR epidemiology network meeting.

b. Registry based working group

No new activities to report

c. Services and records-based working group

The group was alerted to the forthcoming (Feb 2007) publication of three papers from CDC and the ADDM network describing new prevalence data on autism spectrum disorders derived from a multi-site study.

d. Website and listserv

The approval for the use of the CDC logo on this site is nearing finalization and notice about the website will be sent to the listserv (EPINET@autismspeaks.org).

3. Miscellaneous updates:

- a. Contacts in Uganda -Members of the sub-committee are assisting and facilitating the development of networking opportunities and introductions of Ugandan researchers to other members of the international epidemiology research community including other NIH-linked researchers working in Uganda.

ACTION ITEM: sub-committee members to facilitate introductions

b. The forthcoming meeting (Feb 2007) between Autism Speaks and the CDC was discussed. The sub-committee reviewed the preliminary agenda, discussed the benefits of a coordinated approach, and referenced opportunities to highlight the release of the ADDM prevalence data (see above) and continuing CDC efforts to measure prevalence.

c. The group commented on documents relating to the India INCLLEN Program. It was noted that this program is using many of the research protocols that the subcommittee has been proposing as “best practice” protocols. Overall, the INCLLEN program represents a useful model for other studies in developing countries. Members of the subcommittee will plan to attend one of the advisory meetings of this program.

4. IMFAR program and symposium:

a. Epidemiology symposium

It was noted that a draft proposal for a special epidemiology symposium at IMFAR has been sent to the chair of the IMFAR program committee. There was a discussion about the letter of invitation that will be sent to each of the proposed presenters. The letter will provide a tentative agenda for the symposium as well as details about an honorarium and specify what expenses Autism Speaks would reimburse.

ACTION ITEM: Proposed speakers and their contact details will be collated and a letter of invitation drafted.

b. Development of budget for Autism Speaks sponsored travel fellowships for international guests

It was shared with the group that Autism Speaks are developing a formal funding mechanism to support researchers to travel and attend relevant meetings and conferences, such as IMFAR, SRCDD, SFN. When approved, the mechanism for applying for these travel grants will be posted on the Autism Speaks website.

c. Pre-IMFAR epidemiology networking meeting (2nd May 2007)

The draft agenda for this meeting was discussed. Since the agenda would reflect the three working groups, staggering of the sessions (and organizational logistics) should be considered to allow participation in more than one working group session. It was suggested that each working group creates a list of invitees and an agenda that can be circulated to allow participants to select their sessions of interest.

ACTION ITEMS: Working group leaders will generate a list of potential invitees.

5 Miscellaneous items

a. Conference calls

There was a discussion on how to set up conference calls so as to encourage new participants in the working groups. It was decided that dates for conference calls would be listed on the website and invitations sent via the listserv. The setting up a web-based discussion forum would be investigated.

ACTION ITEM: to investigate web-based resources to encourage participation in the working group

b. Naming the group

The committee members will bring suggestions for a name for the group to the next conference call.

Next call scheduled for February 14th 2007

**Conference call
Autism Speaks / CDC Epidemiology Subcommittee**

February 2007

1. Minutes from January 2007 were approved.
2. Working Group Updates

c. Developing Countries

An update on the activities of the India INCLEN group was provided and it was noted that this project is getting ready to pilot test a screening instrument - having modified the familiar 10 question screen into a questionnaire with 22 to 35 items. This group is also working on developing a diagnostic instrument. Autism Speaks offered assistance with issues that may arise and invited the program leader to participate in the developing countries working group. Pilot data are expected to be available at the end of this month.

Tentative plans were discussed for holding a meeting in Delhi in early 2008 as part of a wider globalization effort. Plans to coordinate ADI/ADOS training across India were discussed and are on the agenda for wider discussion at the networking meeting around IMFAR.

It was reported that dialogue has opened with WPS regarding the translation of autism screening and diagnostic instruments for use in developing countries. WPS is interested in working with Autism Speaks to help coordinate plans to translate diagnostic instruments into different languages so that everyone is working together for the same purpose. WPS has already had two groups from India approach them and there are several groups in China competing for rights to translate instruments.

The committee discussed the need to be aware of not only language issues related to translation, but also cultural issues. It was noted that researchers in London are talking about developing screening instruments for developing countries. The importance of letting other people in the community know what the committee has been discussing was highlighted. A member of the epidemiology sub-committee will contact the London based researchers with a view of inviting participation in the developing countries working group.

China mini proposal: It was reported that members of the Birth Defects Branch at CDC have been working on a project in conjunction with Beijing Medical University for the past ten years and following a cohort of 250,000 women and their children prospectively as part of a follow up study of folic acid supplementation to prevent neural tube defects. These children are now 10-12 years old, and a third follow up study is planned and the possibility of including an autism component is being considered. This work has helped

develop infrastructure for surveillance and services for other developmental disabilities and could potentially do the same for autism.

ACTION ITEM: A conference call will be set up for people interested in joining the developing countries working group to begin to formulate an agenda for the pre-IMFAR meeting.

d. Registry-based

Efforts have been made to make contact with researchers interested in joining this working group including researchers in Scandinavia, UK and Israel. Conference calls with the existing participants have been arranged for February 15 and March 15.

c. Services + Records-based

Conference calls have been set March 9 and March 21 with the purpose of formulating an agenda for the pre-IMFAR network meeting.

e. Website www.autismepidemiology.net

ACTION ITEM: Follow up on CDC logo approval

e. Listserv – EPINET@autismspeaks.org

ACTION ITEM: Notice about website sent out to listserv

3. Miscellaneous Updates:

a. Uganda

As per action item from December, networking efforts have been made to introduce Ugandan researchers with contacts at CDC and Autism Speaks and an invitation extended to attend the pre-IMFAR network meeting.

b. AS visit to CDC Feb.

A brief overview was provided of the agenda for this high level meeting between CDC (Dr. Gerberding) and Autism Speaks (Bob Wright) and members of this sub-committee. The two major agenda items for discussion will be support for ongoing CDC epidemiology programs and continued efforts to obtain data for prevalence studies of autism.

c. Saudi Arabia update

A brief trip report was given for a visit to Saudi Arabia (including an invitation from the royal cabinet) which aims to establish and support autism research and services infrastructure. The Saudi Arabian Health Minister has \$1 million budget to conduct the first epidemiological survey of autism in Saudi Arabia. The lead researcher on this project noted that the study was not optimally designed and based on using the ICD-10 diagnosis, which is likely to severely under-report the incidence of autism. The researchers are seeking Autism Speaks' help with framing the findings and designing a better survey.

The committee was informed of a pledge from a foundation affiliated with the royal family for \$600,000 to fund five mentor-based fellowships in epidemiology, phenotype and genetics. The mentorships will be between Western mentors and Saudi fellows.

4. IMFAR program and symposium

- a. The abstract for the special epidemiology symposium at IMFAR has been submitted and the letters of invitation sent out (responses have not been received from all invitees).
- b. A conference call with presenters is planned for further work on organizing the symposium.

ACTION ITEM: Schedule conference call with all presenters

- c. Pre-IMFAR epidemiology meeting draft agenda
A list of invitees is under development and was discussed by the committee. It was agreed that Autism Speaks will reimburse attendees who would not otherwise attend IMFAR, particularly those from outside the US. The logistics for holding this meeting were reviewed.

**Conference call
Autism Speaks / CDC Epidemiology Subcommittee**

March 2007

1. Minutes from February 2007 were approved.

It was agreed to post condensed minutes from working group conference calls on the website.

It was agreed that dates for future working group calls should be posted on the website, with the assumption that call participants would be familiar with the background of the group activities.

ACTION ITEMS: Finalized condensed minutes from September to December 2006 to be posted on website; Preparation of condensed minutes from January and February 2007 to be completed.

2. Updates from the working groups:

b. Developing Countries

It was noted that an issue emerging during the conference calls was the need to focus on how best to develop screening and diagnostic tools for autism that will be effective across cultures and languages.

It was decided that the developing countries working group will be renamed "screening approaches".

c. Registry-based

Reviewed as part of the IMFAR meeting discussion (see below).

d. Services + Records-based

Reviewed as part of the IMFAR meeting discussion (see below).

e. Website

The group was informed that the CDC had approved the use of its logo for the subcommittee website.

4. Miscellaneous updates:

a. Autism Speaks visit to the CDC

A brief overview of Autism Speaks (Bob Wright's) meeting with CDC director (Dr Gerberding) was given and it was noted that CDC funding higher levels of autism research relies on Congress specifically increasing the CDC budget.

b. Autism Hearing, April 17

It was noted that Bob Wright will speak at the upcoming autism hearing.

5. Planning for the IMFAR program and symposium

A conference call is scheduled for March 23.

6. Pre-IMFAR Epidemiology network meeting

a. Agenda and Goals of meeting

There was a discussion about the agenda and goals of the pre-IMFAR epidemiology meeting with general agreement that, before the working groups break out into separate groups, there should be a discussion of some cross-cutting issues for each group.

Committee members decided to make changes to the agenda: i.e.

- As part of 'introductions', a representative from each working group will provide a brief description of the issues facing their groups including a definition of the group's objectives and scope.
- The second section of the meeting will be dedicated to discussion of how to define autism spectrum disorders (and this will also be considered in the breakout sessions).
- A larger part of final session of the day will be dedicated to working group reports, recommendations and discussion of next steps.

There was a review and discussion about the structure of the working group breakout sessions.

b. List of invitees

It was decided the meeting should be invitation only (including all participants on the working group conference calls).

The next call of was scheduled for April 13 2007

**Conference call
Autism Speaks Epi Subcommittee
Agenda**

April 2007

1. Minutes from the March 2007 conference call were approved.

2. Website update
Several new pieces of information have been added to the website and condensed minutes from Sept-Dec 2007 have been linked to the homepage. There is also a notification regarding attendance at the pre-IMFAR networking meeting on May 2nd. The formal notification for use of the CDC logo on the website is imminent.

3. Planning for the pre-IMFAR meeting (2nd May 2007)

a) Developing the agenda

i) Overall agenda for the day

It was agreed the meeting should open with a welcome, introductions and a description of the meeting's purpose followed by an overview of the three working groups, how their goals differ and in particular the distinction between the registry-based and records-based working groups. It was agreed that the working group sessions should be staggered if participants expressed interest in attending multiple sessions.

Subcommittee members then discussed that the next part of the meeting will be devoted to introducing common issues across all working groups. It was agreed it was important to include a speaker addressing cross-cultural issues in autism epidemiology.

ACTION ITEM: A speaker will be approached to speak on the cross-cultural issues of conducting epidemiology studies of autism.

ii) Agendas for the working group sessions

The working group leaders reported these agendas would be finalized by April 27.

iii) Summing up

The group discussed the key points that should be made in the summary period i.e. the working groups should provide a summary of their session and the session accomplishments; Autism Speaks should provide a summary for the case for supporting epidemiology research including support for the epidemiology network (website and listserv) and an affirmation for continued support the annual pre-IMFAR epidemiology meeting and introduce creative ways to facilitate the funding of projects that arise out of the network.

It was suggested the concluding session should cover the structure of the working groups and how to proceed.

b) List of invitees

Approximately 70 people have formally responded.

c) Logistics

The logistics for the day were discussed.

ACTION ITEMS: Agendas for the working group breakout sessions finalized by April 27; Expansion of the subcommittee membership to be considered.

4. IMFAR epidemiology symposium

Members of this sub-committee are setting goals for the discussion items.

5. Miscellaneous

a) Autism Hearing April 17—the group was informed that representatives from CDC, Autism Speaks and NIMH will be present at this congressional hearing. Feedback will be provided to the committee.

b) The name for the group was approved as International Autism Epidemiology Network.

The next call will be May 21 at 1 p.m. EST

**Conference call
Autism Speaks Epidemiology Subcommittee
Minutes**

May 2007

1. Comments on the minutes from April 2007 were invited.
2. Reports from the working group breakout sessions held at the pre-IMFAR meeting
 - a. *Screening working group (formerly developing countries)*

The key recommendation was for Autism Speaks to take the lead in facilitating a process to develop a standardized screening protocol/tool that could be used across different countries for example through creating a RFP or RFA mechanism.

ACTION ITEM: Prepare a short written summary describing the goals identified by this working group and how these might be achieved for use within Autism Speaks to facilitate strategic planning.

- b. *Registry-based working group*

The group was briefed on the summary created at the end this working group's breakout session. It was highlighted that the group quickly gelled and identified several robust proposals and recommendations for moving forward, These included Autism Speaks continuing to support the network through web-based forums and meetings, creation of a 'registry of registries' and supporting collaboration among a group of investigators, using several registries, to examine a key question about, such as the link between autism and parental age.

ACTION ITEM: Prioritize list of proposals and include cost estimates; determine the resource implications for Autism Speaks to continue to support the network.

- f. *Services + Records-based working group*

It was reported this group did not reach a consensus on how to proceed. It was suggested that funding pilot studies might be helpful and for Autism Speaks to facilitate permissions to access these records for research.

There was a general discussion on priorities. It was agreed that the first step is for information to be available through the website which could be handled by the Autism Speaks epidemiology staff person (when recruited) given that Autism Speaks plans to recruit an assistant director dedicated to managing the epidemiology portfolio.

Subcommittee members discussed the need for a special mechanism outside Autism Speaks' existing mechanisms to support epidemiology research. There was a discussion on the availability of other sources of funding (or lack of them) for large-scale (expensive) epidemiology studies. It was emphasized that epidemiology is research tool to study causation and symptomatology (e.g. GI issues related to autism).

ACTION ITEMS: Possible proposals for funding to be presented to the SAC

5. Next steps for the network
The subcommittee agreed to continue meeting via conference call every other month. Meanwhile, the working groups will begin meeting via web-based chat rooms that Autism Speaks will facilitate.

**Conference call
Autism Speaks Epidemiology Subcommittee
Agenda**

June 2007

1. Minutes

ACTION ITEM: Finalize condensed minutes for publication on the website

2. Feedback from Autism Speaks SAC meeting

a) Follow up on recommendations for funding of projects

It was noted that the SAC had approved funding for the epidemiology subcommittee to move ahead with its work and the group were asked to review their planned activities accordingly. When appropriate the group should open discussions with Autism Speaks on formulating appropriate RFAs.

b) Enhanced website for 3 working groups to "meet"

The concept of creating a web-based forum for researchers in the working groups to meet to continue their work was reviewed. It was proposed that an existing system could be linked to the epidemiology website and customized to meet specific needs. The subcommittee members agreed this software would work and access to the forum should be security protected.

c) Planning for the working groups

i) Screening working group

It was agreed to begin planning for a meeting to be held in 2007 (approximately 30 people) to begin discussing the development of a screening or diagnostic instrument that would cross international lines and be sensitive to cultural issues. A steering committee should be convened to help plan this meeting.

ACTION ITEM: A call to be set up to discuss forming a steering committee to plan the first meeting

ii) Registry based working group

The idea of creating a registry of registries was discussed and the use of a series of meetings to bring researchers together to use registries to analyze a specific research issue that might be amenable to this approach. A meeting is planned to initiate a collaborative project and develop a proposal. In response to a query about how this project might be funded, the group agreed that interested researchers

should write a proposal that would be peer reviewed, but this does not need to go through a traditional competitive process for funding.

ACTION ITEM: Next steps for planning a first meeting of researchers interested in a collaborative project.

iii) Records-based working group

It was recommended this group examine a mechanism to fund pilot studies to look at the feasibility of using a records-based approach in other countries. This mechanism would allow researchers to identify the records structure in various countries to find out what is available and evaluate whether the records are useful for conducting epidemiological studies. Following the publication of the full request for applications, researchers who are interested in submitting proposals would be brought together to discuss feasibility and evaluation.

ACTION ITEM: Discuss with Autism Speaks developing an RFA.

3. The Autism Speaks and International Epidemiology Network websites should be linked and there should be a website for the epidemiology subcommittee

The next subcommittee call will be August, 10 1:00 EST.

The following meeting will be Oct. 12 at 1:00 EST.