

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

September 2006

1. Minutes from August 2006 were approved.

2. Updates from the working groups

a. Developing countries working group

There was a discussion on the significant issues in conducting research in these countries and this discussion mainly focused on the problems with case definitions of autism in different countries and the broader definition of other developmental disorders. Contact will be made with experienced service providers and researchers to seek their guidance. Initial contact will be made with a group working in India with the objective of holding meetings in India to discuss case definitions, service delivery and engaging support for autism research from local establishments and the government.

b. Registry based working group

The focus of this sub-group is to promote the application of registry-based research in countries where such registries are available. This can be achieved through enhancing the autism research community's knowledge and access to these registries, by providing an inventory of registries available in different countries and providing researchers with an assessment of the completeness and validity of these registries. Registries could also be linked with other databases (such as biobanks) to expand their applicability.

c. Services and records based working group

The focus of this sub-group is to improve the understanding of the characteristics and prevalence of ASD using a population-based, multiple source methodology. The goal would be to develop a general model for determining cases of ASD that can be used world-wide, where feasible. A possible model could include:

- The collection and review of information from children's evaluation records from medical, educational and social services agency records.
- Examination of these records for symptoms consistent with predetermined criteria for autism.
- A description of the characteristics of children and their families to permit comparison across sites.
- The ability to perform clinical evaluations of children in order to validate the records based approach to prevalence surveillance.

d. Development of a dedicated website for the Epidemiology Sub-committee

There are two basic components to the website: i) a basic home page to provide information to the public, including contact information as well as descriptions of the working group's primary initiatives; ii) an informatics portal for researchers.

The Listserv continues to be updated regularly.

3. Miscellaneous Updates

a. Mexico

CLIMA, a non-profit organization, is the main provider of clinical services for the autism community in Mexico. Autism Speaks is talking to CLIMA to explore collaborative efforts in helping Autism Speaks advance its mission in Mexico. Other organizations are also being approached and the idea of an international autism research conference in Mexico City in 2007 is being explored (as a way to introduce Autism Speaks) to the Mexican autism community and to position Autism Speaks for future interactions with Mexican government agencies and private foundations.

b. Taiwan

Opportunities have been explored for Autism Speaks to collaborate on an epidemiological study in Taiwan. This would be beneficial since i) Taiwan has a strong public health registry, covering >98% of the population, making a registry based epidemiology study relatively inexpensive; ii) a study in some of the Southern Taiwan counties could reach about 2.5 million people out of a total population of 23 million on the island; iii) studies in Taiwan would provide a unique scientific opportunity to examine the effects of environmental exposures (this country has a high rate of fossil fuel emissions per capita).

Autism Speaks has been approached to sponsor a special autism symposium at the 45th annual meeting of the Taiwanese Society of Psychiatry (Nov 2006) and to host a conference dinner with invitations extended to key government representatives and advocates who will help explore possible collaboration and support for AS efforts in Taiwan. The National Science Council of Taiwan is assisting.

The group also noted that epidemiologic studies in Eastern Europe and the former Soviet countries (which are under-studied) may also provide scientific opportunities to examine environmental factors.

4. Activities planned at the IMFAR 2007 Meeting

It was suggested that Autism Speaks host an epidemiology symposium and also a dedicated workshop immediately prior to the meeting and that planning for these activities should begin.

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

October 2006

1. The minutes from September 2006 were approved.

2. General points

- Research into 'environmental issues' should fall under the list of topics for this committee to discuss and researchers with expertise in this area should be invited to join the group.
- There was a decision that many of the activities of the working groups can be achieved through e-mails and conference calls. A face-to-face meeting would be most valuable after the working groups have been fully established.

3. Updates from the working groups

a. Developing countries working group

The need for this group to address the issue of developing case definitions for autism in developing countries was reiterated.

Members of the INCLLEN (India) program are planning a meeting in late 2007 / early 2008 with the aim of bringing together clinicians and researchers to increase the infrastructure for autism research and care in India. It was noted that INCLLEN is an existing network and is a possible model that could be applied to other countries. The epidemiology subcommittee should explore facilitating the linkage of autism epidemiology activities to the existing INCLLEN network. An invitation will be extended to a researcher linked to INCLLEN to provide the committee with more specific information about the INCLLEN network.

b. The group discussed how to expand membership of the developing countries working group as well as each of the other two working groups: *Registry-based and Services and records-based (working groups)*

c. Website development

Compilation of the material to be included on the website is nearing completion and will be reviewed by the group. The listserv continues to be developed.

3. Miscellaneous updates

a. Mexico

Representatives from Autism Speaks and the Telmex Foundation met. The number of autism cases predicted (using the current US estimates) for Mexico City should be around 50,000 cases, versus only about 600 known cases at the main autism treatment center. These figures emphasized the urgent need for epidemiologic studies.

b. Uganda

CDC scientists on the subcommittee made an initial contact with a professional healthcare worker in Uganda to explore possible collaborative studies. In order to develop epidemiologic studies in Uganda it was pointed out that one possibility might be to 'piggy back' autism epidemiologic studies focusing on maternal infection/inflammation by sharing infrastructure with on-going studies that are investigating maternal AIDS. The group will explore this further.

4. IMFAR related activities

Planning continues for the epidemiology symposium as a formal part of the IMFAR 2007 meeting and on the specific AS/CDC sponsored workshop to be held May 2, the day before IMFAR.

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

December 2006

1. Minutes from October 2006 were approved.

2. Updates from the working groups

a. Developing countries working group

A summary was provided of the visit by an NIH representative to a researcher in Uganda, with a focus on exploring possibilities for conducting autism surveillance in that country by adapting the protocol being developed by INCLIN. The group discussed that an epidemiologic study in Uganda would require careful planning and establishment of the appropriate infrastructure. Validation of the screening instruments would be necessary and the group discussed the possibility that assistance could be provided by experienced US researchers willing to engage in this project. Such studies could provide valuable information on environmental factors such as prenatal and perinatal infections that are more common in Uganda and may be a more important risk factor for autism in Uganda.

The group discussed the importance of performing surveillance in Uganda where there is a lack of information and robust data on childhood disabilities and related pathology.

b. Registry-based working group

A review of activities relating to contacting participants for the IMFAR symposium and there was a discussion of providing support / fellowships for travel expenses. Opportunities to collaborate in an on-going registry-based study in Norway and Denmark were raised.

c. Services and records-based working group

There were no new activities.

d. Website

The listserv continues to be updated and members will be notified about the link to the website.

3. Miscellaneous updates

a. Autism Speaks visits CDC

The group discussed the scope of the upcoming meeting between representatives of Autism Speaks and CDC and noted that key agenda items would include presenting an overview of CDC surveillance, research and awareness programs.

4. IMFAR program and symposium

a. Formal epidemiology symposium

The proposed symposium had been accepted by the IMFAR organizing committee. The key participants need to sent specifics related to the symposium followed by a more general announcement about IMFAR..

b. Development of Autism Speaks sponsorship of travel fellowships for international guests
There was a discussion about travel fellowships and development of a formal mechanism by Autism Speaks to allocate these awards.

c. Pre-IMFAR workshop

The draft agenda will be reviewed on the January 2007 call.

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

November 2006

1. Minutes from October 2006 were approved.

2. Updates from the working groups

a. Developing countries working group

The INCLLEN network has developed a proposal which Autism Speaks and other groups have funded. The proposed project will consist of two phases: the first will develop and pilot test screening tools; the second will take the tools that they've developed and use them to conduct a door-to-door survey in the five Indian provinces.

The INCLLEN research team recently held a three day workshop in India to discuss the first phase of the project, bringing in participants from Uganda and China. Minutes from that meeting will be shared with the epidemiology subcommittee.

It was noted that the opportunity to study autism in a large cohort in China might exist. More details will be obtained.

b. Registry-based working group

No new activities to report.

c. Services and records-based working group

No new activities to report.

d. Website

The website is being finalized and the launch is imminent. Notice has been sent to the *Listserv members*.

3. Misc. Updates

a. Uganda

An initial contact with a healthcare professional had been followed up by a representative of the epidemiology subcommittee and a dialogue opened. The group discussed opportunities for an epidemiologic study that could be generated through this connection. The group was reminded of an earlier discussion on opportunities to investigate any potential link between HIV and autism in developing countries.

b. India and the ADI

The group discussed that a language / translation barrier to autism research exists in India. The ADI-R, one of the main research instruments for autism is validated in English and Spanish only. Whilst India has a large English speaking population for which the existing ADI-R can

be used, there is a lack of ADI-R certified professionals who are eligible to use the ADI-R. This problem is also under discussion by the Autism Tissue Program Executive Committee related to the need to have autism confirmation on cases for brain banking activities in India.

The discussion continued with a focus on more general points regarding the significant challenges in performing robust autism research in non-English speaking countries and in particular in developing countries. The subcommittee discussed how to promote research, with the need to develop diagnostic protocols that are valid across cultures and languages. The group noted the difficulties and discussed alternatives to translating the ADI-R model, including developing a shorter screening protocol. The group agreed to hold a more detailed discussion, perhaps via a dedicated symposium or other forum open to experts.

d. Mexico

The meeting planned in Mexico City will occur July 4-6 2007 and the incoming first lady of Mexico has agreed to speak at the opening ceremony.

3. IMFAR program and epidemiology symposium

The group reviewed the outline of the IMFAR meeting (Seattle, May 2007). The group discussed the agenda and scope of the special epidemiology symposium organized by the Autism speaks / CDC sub-committee and the allocation of travel fellowships for researchers to attend this meeting.