

Meeting of the Interagency Autism Coordinating Committee

December 14, 2010

The Bethesda Marriott
5151 Pooks Hill Road
Bethesda, MD 20814

Conference Call Access:

Phone: (888) 577-8995

Access Code: 1991506

Meeting of the IACC

Morning Agenda

- 9:00** *Registration Desk Opens*
- 10:00** Call to Order and Opening Remarks
Thomas Insel, M.D., Chair, IACC
- 10:10** Review and Approval of October 22, 2010
Minutes
- 10:15** Strategic Plan Update - Discussion and Votes
- 12:00** Lunch

Recent Autism Science

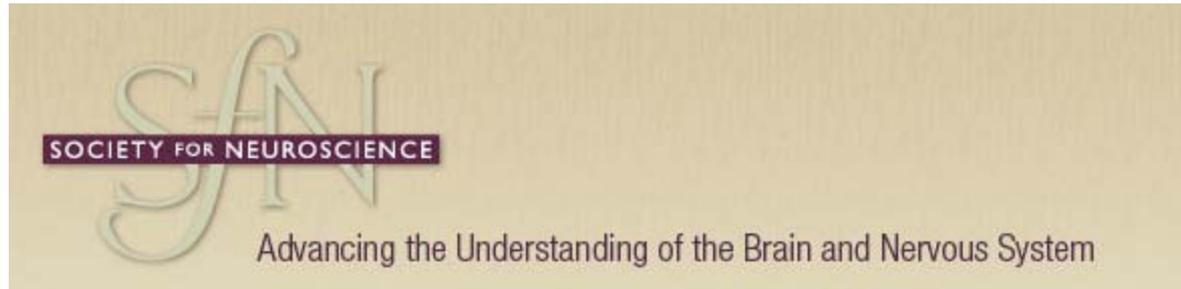
Thomas Insel, M.D.

Chair, IACC

IACC Full Committee Meeting

December 14, 2010

Autism “Hot Topic” at SFN



In 2009: 255 abstracts

In 2010: 337 abstracts
and a public symposium

A Model for Neural Development and Treatment of Rett Syndrome Using Human Induced Pluripotent Stem Cells

Maria C.N. Marchetto,^{1,5} Cassiano Carromeu,^{2,5} Allan Acab,² Diana Yu,¹ Gene W. Yeo,³ Yangling Mu,¹ Gong Chen,⁴ Fred H. Gage,¹ and Alysson R. Muotri^{2,*}

¹The Salk Institute for Biological Studies, 10010 North Torrey Pines Road, La Jolla, CA 92037, USA

²University of California San Diego, School of Medicine, Department of Pediatrics, Rady Children's Hospital San Diego, Department of Cellular and Molecular Medicine, Stem Cell Program, 9500 Gilman Drive, La Jolla, CA 92093, USA

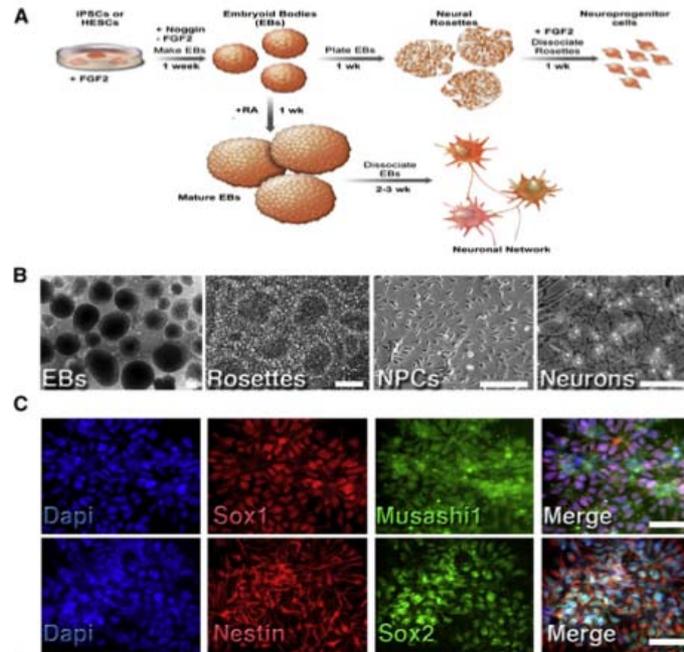
³University of California San Diego, School of Medicine, Department of Cellular & Molecular Medicine, Stem Cell Program, 9500 Gilman Drive, La Jolla, CA 92093, USA

⁴Pennsylvania State University, Department of Biology, 201 Life Science Building, University Park, PA 6802, USA

⁵These authors contributed equally to the work

*Correspondence: muotri@ucsd.edu

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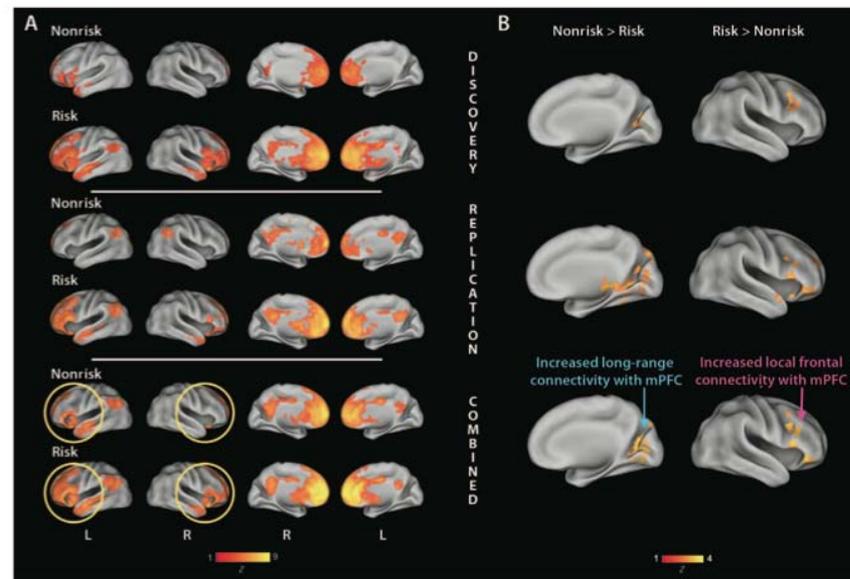
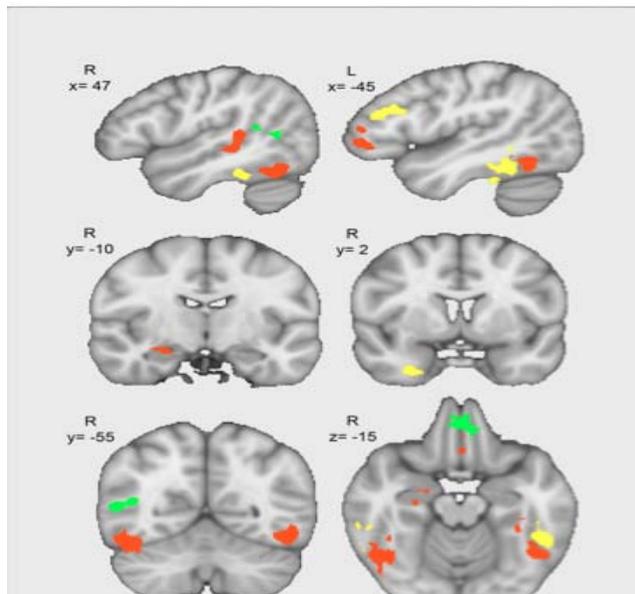
Rescue with
IGF1 and Gentamycin

Neural signatures of autism

PNAS 12/7/10

Martha D. Kaiser^a, Caitlin M. Hudac^a, Sarah Shultz^{a,b}, Su Mei Lee^{a,b}, Celeste Cheung^a, Allison M. Berken^a, Ben Deen^a, Naomi B. Pitskel^a, Daniel R. Sugrue^a, Avery C. Voos^a, Celine A. Saulnier^a, Pamela Ventola^a, Julie M. Wolf^a, Ami Klin^a, Brent C. Vander Wyk^a, and Kevin A. Pelphrey^{a,b,1}

^aYale Child Study Center, Yale School of Medicine, New Haven, CT 06520, and ^bDepartment of Psychology, Yale University, New Haven, CT 06520



Altered Functional Connectivity in Frontal Lobe Circuits Is Associated with Variation in the Autism Risk Gene *CNTNAP2*

Ashley A. Scott-Van Zeeland,^{1,2,3} Brett S. Abrahams,^{4*} Ana I. Alvarez-Retuerto,^{4,5} Lisa I. Sonnenblick,⁴ Jeffrey D. Rudie,² Dara Ghahremani,⁶ Jeanette A. Mumford,⁷ Russell A. Poldrack,⁷ Mirella Dapretto,^{5,6,8} Daniel H. Geschwind,^{4,5††} Susan Y. Bookheimer^{1,5,6,7††}

(Published 3 November 2010; Volume 2 Issue 56 56ra80)

Describing the Brain in Autism in Five Dimensions—Magnetic Resonance Imaging-Assisted Diagnosis of Autism Spectrum Disorder Using a Multiparameter Classification Approach

Christine Ecker,¹ Andre Marquand,² Janaina Mourão-Miranda,^{3,4} Patrick Johnston,¹ Eileen M. Daly,¹ Michael J. Brammer,² Stefanos Maltezos,¹ Clodagh M. Murphy,¹ Dene Robertson,¹ Steven C. Williams,³ and Declan G. M. Murphy¹

¹Section of Brain Maturation, Department of Psychological Medicine, Institute of Psychiatry, ²Brain Image Analysis Unit, Department of Biostatistics, Institute of Psychiatry, and ³Centre for Neuroimaging Sciences, Institute of Psychiatry, King's College, London SE5 8AF, United Kingdom, and ⁴Centre for Computational Statistics and Machine Learning, Department of Computer Science, University College London, London WC1E 6BT, United Kingdom

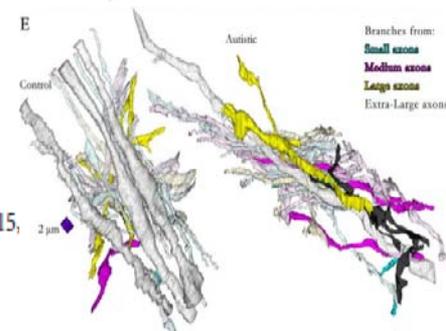
The Journal of Neuroscience, November 3, 2010 • 30(44):14595–14609 • 14595

Neurobiology of Disease

Changes in Prefrontal Axons May Disrupt the Network in Autism

Basilis Zikopoulos^{1,2} and Helen Barbas^{1,2,3}

¹Neural Systems Laboratory and ²Program in Neuroscience, Boston University, Boston, Massachusetts 02215, Research Center, Harvard Medical School, Boston, Massachusetts 01772



Mitochondrial Dysfunction in Autism

Cecilia Giulivi, PhD

Yi-Fan Zhang, BS

Alicja Omanska-Klusek, MS

Catherine Ross-Inta, BS

Sarah Wong, BS

Irva Hertz-Picciotto, PhD

Flora Tassone, PhD

Isaac N. Pessah, PhD

Context Impaired mitochondrial function may influence processes highly dependent on energy, such as neurodevelopment, and contribute to autism. No studies have evaluated mitochondrial dysfunction and mitochondrial DNA (mtDNA) abnormalities in a well-defined population of children with autism.

Objective To evaluate mitochondrial defects in children with autism.

Design, Setting, and Patients Observational study using data collected from patients aged 2 to 5 years who were a subset of children participating in the Childhood Autism Risk From Genes and Environment study in California, which is a population-based, case-control investigation with confirmed autism cases and age-matched, genetically unrelated, typically developing controls, that was launched in 2003 and is still ongoing. Mitochondrial dysfunction and mtDNA abnormalities were evaluated in lymphocytes from 10 children with autism and 10 controls.

 AUTISM SPECTRUM DISORDERS

Parental Autoimmune Diseases Associated With Autism Spectrum Disorders in Offspring

Epidemiology 9/10

*Alexander Keil,^a Julie L. Daniels,^{a,b} Ulla Forssen,^{c,d} Christina Hultman,^e Sven Cnattingius,^f
Karin C. Söderberg,^g Maria Feychting,^d and Par Sparen^e*

PNAS 6/10

Characterization and reversal of synaptic defects in the amygdala in a mouse model of fragile X syndrome

Aparna Suvrathan^a, Charles A. Hoeffler^b, Helen Wong^b, Eric Klann^b, and Sumantra Chattarji^{a,1}

^aNational Centre for Biological Sciences, Bangalore 560065, India; and ^bCenter for Neural Science, New York University, New York, NY 10003

Introduction for the Strategic Plan Update

Thomas Insel, M.D.

Chair, IACC

IACC Full Committee Meeting

December 14, 2010

IACC Strategic Plan

- Date due: Required annually
- Sources of information for updates:
 - Portfolio Analysis – Gaps
 - IACC Summary of Advances in ASD Research – Opportunities
 - IACC Public Comments/IACC Meetings – Needs
 - Policy Changes – Opportunities and Needs

Annual Strategic Plan Update Process

- **Planning Subcommittee Tasks:**
 - Review of relevant data
 - Update consists of an addendum for each chapter following the format:
 - What is new in this research area and what have we learned this past year?
 - What gap areas have emerged since last year?
 - What new research opportunities and research objectives have emerged?
 - **2010 Planning Subcommittee Meetings:**
 - April 19, June 18, September 21, October 6, November 19, and December 3

Major issues

- Scope of update
- Policy changes (Affordable Care Act)
- Issues needing attention:
 - Disorder/Disability
 - Co-morbid/Co-occurring conditions
 - Community-based participatory research
 - Comparative effectiveness research

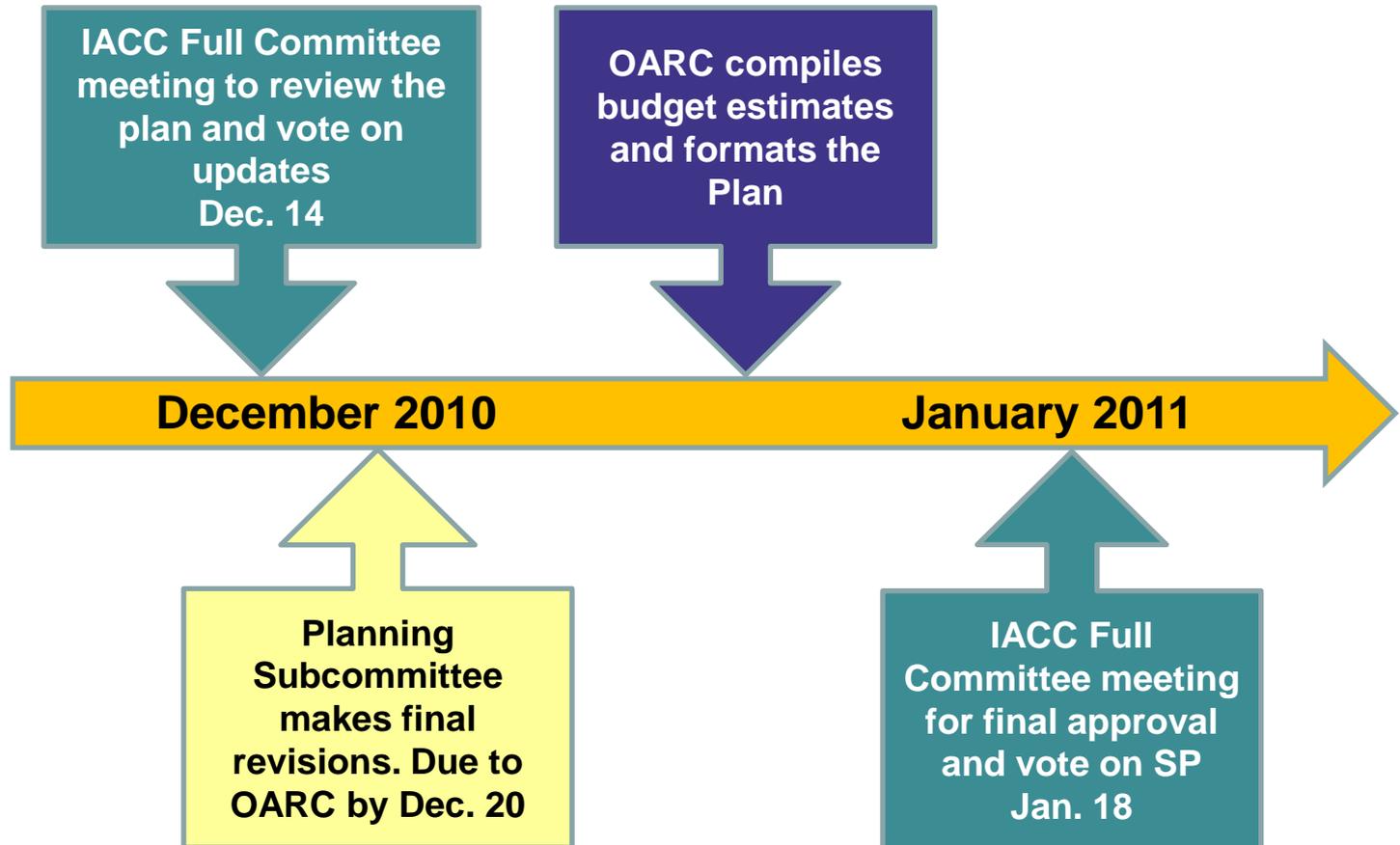
Managing Expectations

- The IACC Research Strategic Plan is advisory and provides guidance for funders.
- The IACC does not fund research or have a research budget.
- The funding climate is undergoing dramatic change with uncertainty about extent of federal support for biomedical research in FY11 and FY12.
- Impact of the Research Strategic Plan will depend on making a compelling case for need, opportunity, and traction.

Process for Strategic Plan Updates

- Review Chapter Updates
- Discuss
- Vote

Timeline for the 2011 Strategic Plan Update



Lunch Break

Afternoon Agenda

- 1:00** Public Comments
- 1:30** Strategic Plan Update – Discussion and Votes
- 3:00** Break
- 3:15** Update: Report on Somali Community Autism Issue
Coleen Boyle, Ph.D., Linda Birnbaum, Ph.D., and
Geraldine Dawson, Ph.D.
- 3:30** Update: IACC Subcommittee on Safety
Lyn Redwood, R.N, M.S.N, and Alison Singer, M.B.A.
- 4:00** Update: IACC Services Subcommittee
Ellen Blackwell, M.S.W., and Lee Grossman
- 4:30** Public Comments Discussion Period
- 5:00** Adjournment

Meeting of the IACC

Open Session for Public Comment

Meeting of the IACC

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Report from IACC Subcommittee on Safety

December 14, 2010

Alison Singer, M.B.A.

Lyn Redwood, R.N., M.S.N.

Co-Chairs, Subcommittee on Safety

Safety Subcommittee

- Safety Subcommittee commissioned at October 22 IACC meeting after presentation on autism-related wandering by National Autism Association
- Focus on issues related to safety of individuals with ASD, (including wandering, restraint, seclusion, etc.
- First task: draft letter to Secretary regarding autism-related wandering

Draft Letter to HHS Secretary

- Includes tragic story of the wandering death of Mason Medlam, as shared by Sheila Medlam at October IACC meeting
- Includes names of other children who died as a result of autism-related wandering
- Discusses overall wandering issues
- Calls for 3 action items

Draft Letter to HHS Secretary

- Collect data on ASD-related wandering
- Develop and test programs to prevent wandering incidents (parent training, individual training, first responder training)
- Coordinate with the Department of Justice to expand AMBER alerts to include children with autism who have wandered

Draft Letter to HHS Secretary

- Develop medical subclassification coding or general medical coding for ASD wandering and similar neurological disorders
- Work with Department of Education to develop guidelines regarding parental notification of wandering or fleeing incidents in schools

Actions Taken

- Safety Subcommittee met November 29
- Safety Subcommittee submitted suggested 4 new objectives to the Planning Subcommittee. These were considered at the Dec. 3 meeting of the Planning Subcommittee.

Action Items

- Review and finalize letter to HHS secretary
- Discuss/approve meetings with DOJ and ED by Safety Subcommittee co-chairs
- Discuss other tasks for Safety Subcommittee (RFI, Seclusion/Restraint, etc.)

Services Subcommittee Update

Ellen Blackwell, M.S.W.

Lee Grossman

Co-Chairs, Services Subcommittee

IACC Full Committee Meeting

December 14, 2010

2010 IACC Services Workshop: Building a Seamless System of Quality Services & Supports Across the Lifespan

- November 8, 2010 – Rockville, MD
- Workshop Slides available at:
<http://iacc.hhs.gov/events/2010/services-subcommittee-workshop-slides-nov8.shtml>
- VideoCast available at:
<http://iacc.hhs.gov/events/2010/services-subcommittee-workshop-slides-nov8.shtml>

Goals of the Workshop

- Inform *Recommendations for the Secretary* (Draft 2/09)
- Services Subcommittee to prepare draft of initial recommendations in early 2011
- Possible second workshop – Spring 2011 on other service-related topics

Introductory Session

Where We Are Today and Where We Want to be in Ten Years

- **Nancy Thaler**, National Association of State Directors of Developmental Disabilities Services
- **Bill East**, National Association of State Directors of Special Education
- **K. Charlie Lakin**, Research and Training Center on Community Living, University of Minnesota – National Core Indicators and ASD

Presentation 1: Self Direction

- **Michael Head**, Michigan Mental Health and Substance Abuse Administration Department of Community Health
- **James Conroy**, Center for Outcome Analysis – Havertown, Pennsylvania

Presentation 2: Standardized Assessment

- **Don Clintsman, Washington Division of Developmental Disabilities**

Presentation 3: Prevention of Seclusion and Restraint

- **Kevin Ann Huckshorn, Delaware Health and Social Services, Division of Substance Abuse and Mental Health**

Presentation 4: Direct Service Workforce Training

- **Carrie Blakeway**, The Lewin Group,
and **Erika Robbins**, Ohio Department
of Job and Family Services

Presentation 5: Housing Options

- **Sheldon Wheeler**, Maine Bridging Rental Assistance Program
- **Joseph Wykowski**, Community Vision – Portland, Oregon

Presentation 6: Peer Supports

- **Lisa Crabtree**, Towson University
Center for Adults with ASD
- **Jim Sinclair**, Autism Network
International
- **Julie LaBerge**, Bonduel School
District, Wisconsin

Presentation 7: Systems Integration

- **John Martin**, Ohio Department of Developmental Disabilities

Proposed Spring 2011 Services Workshop

- Person-centered policy and planning
- Employment and vocational opportunities
- Managed care delivery systems
- Criminal justice diversion
- Direct service certification -
Department of Labor

Spring 2011 Workshop

(continued)

- Recreational and service programs
- Diversity issues and cultural competence
- Home and community-based services characteristics and ASD
- Americans with Disabilities Act/*Olmstead*

Spring 2011 Workshop

(continued)

- Family support
- Infrastructure
- Community inclusion
- Department of Defense programs
- Emergency preparedness
- Wandering, early warning system for wandering



2010 IACC SERVICES WORKSHOP:

**Building a Seamless
System of Quality
Services & Supports
Across the Lifespan**

November 8, 2010

Hilton Rockville Hotel
Executive Meeting Center
1750 Rockville Pike
Rockville, MD 20852

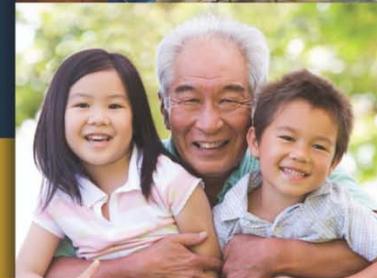
9:00 am – 5:30 pm

Topics include:

- Where We Are Today and Where We Want to be in 10 Years
- Self-Direction
- Standardized Assessment
- Prevention and Reduction of Seclusion and Restraint
- Direct Services Workforce Training
- Housing Options
- Peer Supports
- Systems Integration

For more information see our website at
www.iacc.hhs.gov

To register go to
www.acclaroresearch.com/iacc/servicesworkshop



Meeting of the IACC

Public Comments: Discussion Period

Meeting of the IACC

Afternoon Agenda

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- 5:00** **Adjournment**

•This meeting may end prior to or later than 5:00 PM ET, depending on the needs of the committee.

Upcoming IACC Meetings

Full IACC Meetings

- January 18, 2011
- April 19, 2011
- July 19, 2011

Meeting of the IACC

Adjournment