

IACC Town Hall Meeting

May 3, 2008

Sacramento CA

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**National Institute of Environmental Health
Sciences (NIEHS)**
IACC Meeting May 12, 2008



Autism Town Hall Meeting: Goals and Products

- **Solicit public input on autism treatment research priorities for Strategic Plan**
- **Prepare summary of recommendations to IACC at May 12th meeting**
- **Use summary to help inform further development and refinement of the Strategic Research Plan**

Who planned the meeting?

- **Organizing Committee**
 - IACC federal representatives—NIEHS, NIMH
 - IACC public members—Lee Grossman and Lyn Redwood
 - UC Davis/M.I.N.D. Institute faculty and staff
- **Other contributors**
 - IACC members
 - NIH Autism Coordinating Committee
 - Autism Speaks
 - National Autism Association

Why Sacramento?

- Geographic balance
- Critical mass of autism researchers and infrastructure
 - UC Davis/M.I.N.D. Institute
 - NIEHS/EPA-funded Children’s Center for Environmental Health and Disease Prevention
 - NIH-funded STAART Center, Autism Center of Excellence
- Active parent and advocacy communities

Meeting Format

- Introduction to Strategic Planning Process
- Series of three panel discussions
- Public comments and questions after each panel
 - Three hours devoted to open dialog

Panel Themes and Goals

- **Themes**
 - **Panel I: ASD treatment in young children**
 - **Panel II: ASD intervention, beyond the young child**
 - **Panel III: Summary and Open Dialog with public**
- **Common Goals**
 - **Stimulate discussion about the range of treatments being used**
 - **Develop recommendations about research priorities including issues of efficacy and safety.**

Panel I members

- **Michael Chez**, *Director of Pediatric Neurology, Sutter Memorial and Sutter Neuroscience Medical Group*
- **Sally Rogers**, *Professor of Psychiatry and Behavioral Sciences, M.I.N.D. Institute, UC-Davis Medical Center*
- **Randi Hagerman**, *Professor of Pediatrics, Medical Director, M.I.N.D. Institute, UC Davis Medical Center*
- **Lynne Mielke**, *founder, Developmental Spectrums East Bay Medical Clinic, Pleasanton CA*
- **Nancy Duley**, *parent/advocate*
- **Claire Bothwell**, *parent/advocate*
- **Lyn Redwood**, *IACC public member, cofounder, coalition for SAFE MINDS*

Panel I highlights

- Biomedical and psychiatric comorbidities associated with ASD—consider ASD as a multi system disorder
- Autism Heterogeneity—need research to match symptoms with treatments
- Vaccines as risk factors
- Novel treatments with reported benefit by DAN! physicians
- Role of toxicants/xenobiotics
- Novel research approaches
- Infrastructure and capacity needs
- Training and education

Panel II members

- **Isaac Pessah, Director, UC Davis Center for Children's Environmental Health and Disease Prevention**
- **Pilar Bernal, ASD Regional Director, Kaiser Permanente, Northern California**
- **Ruth Christ Sullivan, first president, Autism Society of America; founder and first executive director, now president of Autism Services Center, Huntington, WV**
- **Dena Gassner, ASD advocate, Director, Center for Understanding, Franklin TN**
- **Rick Rollens, parent cofounder UC Davis M.I.N.D. Institute**
- **Lee Grossman, IACC public member, president and CEO, Autism Society of America**

Panel II highlights

- Screening, diagnosis and assessment of ASD across the lifespan
- Multidimensional services research
- Quality of life (QOL)--better ways to measure and treatments to improve QOL
- Developmental needs of individuals with ASD across the lifespan
 - Adolescence, aging
 - Chronic biomedical conditions
- Effective supports for higher functioning individuals with ASD
 - Employment, postsecondary education
- Inclusion of individuals with ASD in priority setting
- Economic research to establish benefit

Other recommendations

- Increase capacity for service and care providers
- Enact legislation to increase funding for services
- Increase acceptance by and in the community
- Raise awareness of unique needs and concerns of higher functioning individuals with ASD, especially in areas of employment and secondary education
- Help individuals and family members to learn about and access available services

How do we use this information?

- Reinforce consumer focus and guiding principles adopted for SP
- Prioritize SP treatment initiatives
- Refine individual initiatives
 - Ensure that funding mechanisms are matched to consumer needs
- Evaluate SP progress
 - Do parents have better information about treatment choices?
 - Are clinicians able to match individuals with effective treatments?

Summary & Next Steps

- Meeting was a success
 - Excellent attendance by public (125-150)
 - Wide range of opinions expressed in a safe environment
 - Many expressed appreciation to IACC for the opportunity to be heard
- Need to build on this success
 - Consider how to sustain ongoing dialog of IACC with public