

MAXINE KURODA



Rehabilitation Institute of Chicago

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12 November 2007

Dear MSSRP and RTP Program Chairs:

We would be delighted to serve as mentors for the Medical Student Summer Research Program and Research Thesis Program. Our past experience with students has been favorable. They have been hard-working and do their best to contribute to research projects. In turn, we hope that our former students have found that their work with us has been rewarding. We appreciate the value of research and wish to convey this to medical students. Some knowledge of research will enable students to gain a better understanding of the scientific literature and how best to apply the findings to the clinical setting. In this way, they can enrich their own practices, and extend the benefits of research efforts to a greater number of patients.

We look forward to your reply.

Sincerely yours,

A handwritten signature in cursive script that reads "Maxine M. Kuroda".

Maxine M. Kuroda, Ph.D., M.P.H.
Epidemiologist/Clinical Research Coordinator
Assistant Professor
Feinberg School of Medicine
Rehabilitation Institute of Chicago
345 E. Superior St. #1176
Chicago, IL 60611

A handwritten signature in cursive script that reads "Deborah J. Gaebler-Spira".

Deborah J. Gaebler-Spira, M.D.
Attending Physician
Professor
Physical Medicine & Rehabilitation
Rehabilitation Institute of Chicago
345 E. Superior St. #1130
Chicago, IL 60611

Attachments

**Medical Student Summer Research Program (MSSRP)
and Research Thesis Program (RTP)
Mentor Information**

- 1) Research description (maximum 1 page):
 - a) General research description
 - b) Description of potential MSSRP or RTP student projects

- 2) Cover letter explaining the reasons for your interest in becoming a mentor

- 3) Current Biosketch

- 4) Trainees over the past 5 years (undergraduate, medical or graduate students; post-doctoral fellows)

Research area (check all that apply):

- Basic Science
- Translational Science (epidemiology)
- Clinical Science
- Other psychometrics

**Medical Student Summer Research Program (MSSRP)
and Research Thesis Program (RTP) – Mentor Information**

1) Research description

a) General research description – Pediatric cerebral palsy (CP) research at the Rehabilitation Institute of Chicago (RIC)

Consistent with the World Health Organization's International Classification of Functioning, Disability, and Health (known as the ICF model), our studies encompass multiple aspects of CP in children. Our research is in collaboration within RIC (e.g., with the Sensory Motor Performance Program) and with other institutions (e.g., NU, CMH, UIC, U of C), and includes epidemiology, etiology, biomechanical and drug interventions, growth and fitness, care and comfort, and activities and participation.

b) Description of potential MSSRP or RTP projects

The Care & Comfort Caregiver Questionnaire: An assessment of reliability and validity

This is an epidemiologic study that evaluates the psychometric properties (reliability and validity) of an instrument (CareQ-P) designed to measure caregiver perceptions of personal care and activities for pediatric patients. Demographic information on primary caregivers, and demographic and clinical information on patients will be collected and analyzed for associations pertinent to intensity of personal care and effect on activities for pediatric patients with cerebral palsy seen at RIC. The CareQ-P was developed at RIC as an adjunct to measures of functional outcome in order to set goals and to assess the effect of treatment interventions. The 20 items of the CareQ-P are self-administered and are designed to measure the caregiver's difficulties and satisfaction with their child's progress in the areas of Personal Care, Positioning/Transferring, and Comfort. The instrument is easy to administer and score, and can be readily integrated into the clinical setting. Most caregivers are able to complete the questionnaire in less than 10 minutes. The CareQ-P will be compared with the WeeFIM, an 18-item functional outcome measure that assesses the amount of assistance a child needs to perform self-care, mobility, and communication skills within the range considered normal. The WeeFIM is appropriate for use with children without disabilities from 6 months to 8 years; children with developmental disabilities from 6 months to 15 years; and persons of all ages with developmental disabilities and developmental ages less than 7 years. The WeeFIM has been shown to be a reliable and valid measure of disability in children with developmental disorders and can be used to evaluate the outcomes of biomedical, developmental, and psychosocial interventions. Despite these advantages, the WeeFIM must be administered by a health care professional (physician, nurse, or physical therapist) with proper training in the interview technique, takes approximately 20-30 minutes to administer, and does not include items related to pain, community participation, or psychosocial experience (which are included in the CareQ).

The Care & Comfort Caregiver Questionnaire: An assessment for adolescents and adults with spasticity

This is an epidemiologic study to design an adaptation of the CareQ-P for adolescent and adult patients (CareQ-A). Demographic information on primary caregivers, and demographic and clinical information on patients will be collected and analyzed for associations pertinent to intensity of personal care and effect on activities. The project will beta test the CareQ-A on a sample of adolescent and adult patients seen at RIC.

2) Cover letter

Attached.

3) Current biosketch

Attached.

4) Trainees over the past 5 years

a) Second year medical student from SIU on a project that tested the hypothesis that psychosocial functioning is lower in children with surgical resection of *congenital* epileptogenic lesions than in children with resected *acquired* nonepileptogenic tumors. Her work was a collaboration between the epilepsy center and the neurosurgery department at Children's Memorial Hospital. {Abstract attached.}

b) Ph.D. candidate in physical therapy from Turkey who came as a visiting scholar for general research experience. She developed a study to address the research question: Does level of activity and participation differ among children with lower extremity motoric disorders? The study would test the hypothesis that children with lower extremity amputation have higher level of activity and participation than children with CP or other congenital orthopedic problems. She accumulated instruments pertinent to quality of life and other domains in the aforementioned WHO ICF model. She accumulated variables to include when studying co-morbid conditions that often accompany cerebral palsy. She drafted a paper entitled "Treadmill Training with Partial Body Weight Support in Children with Cerebral Palsy." This is a review paper that addresses the use of treadmill training in children with CP. Her review attempts to synthesize the current evidence to guide clinicians about the treadmill training intervention and to foster continued research in this area. {Draft, thus not attached.}

c) Summer extern from Rush did the beta test of the CareQ-P on 15 patients to test its psychometric properties. Her work was helpful in working out the logistics of obtaining informed consent and filling out questionnaires in a busy clinic setting. She developed a log of the patients seen (to avoid duplication in subsequent visits by the same patients) and assisted in identifying items and portions of the questionnaire that required refinement. {Paper attached.}

BIOGRAPHICAL SKETCH

Provide the following information for the key personnel and other significant contributors in the order listed on Form Page 2.
Follow this format for each person. **DO NOT EXCEED FOUR PAGES.**

NAME Kuroda, Maxine Misae		POSITION TITLE Epidemiologist	
eRA COMMONS USER NAME MAXKURODA		Research Assistant Professor, The Feinberg School of Medicine, Northwestern University	
EDUCATION/TRAINING <i>(Begin with baccalaureate or other initial professional education, such as nursing, and include postdoctoral training.)</i>			
INSTITUTION AND LOCATION	DEGREE <i>(if applicable)</i>	YEAR(s)	FIELD OF STUDY
San Jose State University, San Jose, CA	M.A.	1984	Psychology
University of California, Berkeley, CA	M.P.H.	1988	Epidemiology- Biostatistics
Columbia University, New York, NY	M.Phil.	1995	Epidemiology
Columbia University, New York, NY	Ph.D.	2000	Epidemiology

A. Positions and Honors.**Positions**

- 1984-1986 Research Coordinator of Epidemiologic Studies, Northern California Cancer Program, Stanford, CA
- 1988 Intern, Training and Laboratory Program Office, Centers for Disease Control & Prevention, Atlanta, GA
- 1991-1995 Staff Associate, Gertrude H. Sergievsky Center, Columbia University, New York, NY
- 1994-1995 Research Associate II, California Birth Defects Monitoring Program (Cerebral Palsy Project), Emeryville, CA (based in New York, NY)
- 1994-2000 Research Analyst, Department of Anesthesiology, St.Luke's-Roosevelt Hospital Center, New York, NY
- 1995-2000 Staff Associate, Child Neurology, Columbia-Presbyterian Medical Center, New York, NY
- 2000-2006 Epidemiologist, Epilepsy Center and Division of Neurology, Children's Memorial Hospital, Chicago, IL
Research Assistant Professor of Pediatrics
The Feinberg School of Medicine, Northwestern University
- 2006 - Epidemiologist-Clinical Research Coordinator
Research Assistant Professor of Physical Medicine & Rehabilitation/Pediatrics
The Rehabilitation Institute of Chicago
The Feinberg School of Medicine, Northwestern University

Honors

- 1962-1966 State of Hawaii Scholarship, University of Hawaii
- 1962-1966 Selected Studies and Honors Programs, University of Hawaii
- 1980-1984 Minority Biomedical Research Support Grant, San Jose State University
- 1986-1988 Office of Higher Education Grant, University of California at Berkeley
- 1988 Public Health Alumni Association Scholarship (Epidemiology-Biostatistics)
- 1992-1993 United Cerebral Palsy Fellowship
- 2005 American Academy for Cerebral Palsy and Developmental Medicine (AAPDM)
Research and Awards Committee (Elected to Committee September 2005)

B. Selected peer-reviewed publications (in chronological order).

Pinto-Martin J, Kuroda M, Torre C, Paneth N. Nurse screening in the assessment of neurologic abnormality in low birthweight infants. *Paediatr Perinat Epidemiol* 1990;4(4):A22.

Mayer J, Warburton D, Jeffrey AM, Pero R, Walles S, Andrews L, Toor M, Latriano L, Wazneh L, Tang D, Tsai W-Y, Kuroda M, Perera F. Biologic markers in ethylene oxide-exposed workers and controls. *Mutat Res* 1991;248:163-76.

Mayer JL, Boffetta P, Kuroda MM. Comparison of questionnaire-derived and tumor registry-derived smoking histories. *Eur J Cancer* 1992;28(1):116-7.

Sanborn KV, Castro J, Kuroda M, Thys DM. Detection of intraoperative incidents by electronic scanning of computerized anesthesia records. Comparison with voluntary reporting. *Anesthesiology* 1996;85(5):977-87.

Nordli DR, Kuroda M. The ontogeny of ictal semiology in children. *Epilepsia* 1997;38(Suppl. 8):218-9.

Hadzic A, Vloka JD, Kuroda MM, Koorn R, Birnbach DJ. The practice of peripheral nerve blocks in the United States: a national survey. *Reg Anesth Pain Med* 1998;23(3):241-6.

Lesser JB, Koorn R, Vloka JD, Kuroda MM, Thys DM. The interaction of temperature with thiopental and etomidate on extracellular dopamine and glutamate levels in Wistar-Kyoto rats subjected to forebrain ischemia. *Acta Anaesthesiologica Scandinavica* 1999;43(10):989-98.

Reich DL, Bodian CA, Krol M, Kuroda M, Osinski T, Thys DM. Intraoperative hemodynamic predictors of mortality, stroke, and myocardial infarction after coronary artery bypass surgery. *Anesth Analg* 1999;89(4):814-22.

Birnbach DJ, Kuroda MM, Sternman D, Thys DM. Use of atraumatic spinal needles among neurologists in the United States. *Headache* 2001;41(4):385-90.

Birnbach DJ, Matut J, Stein DJ, Campagnuolo J, Drimbarean C, Grunebaum A, Kuroda MM, Thys DM. The effect of intrathecal analgesia on the success of external cephalic version. *Anesth Analg* 2001;93(2):410-3.

Nordli DR, Kuroda MM, Carroll J, Koenigsberger DY, Hirsch LJ, Bruner HJ, Seidel WT, DeVivo DC. Experience with the ketogenic diet in infants. *Pediatrics* 2001;108(1):129-33.

Nordli DR, Kuroda MM, Hirsch LJ. The ontogeny of partial seizures in infants and young children. *Epilepsia* 2001;42(8):986-90.

Lesser JB, Sanborn KV, Valskys R, Kuroda M. Severe bradycardia during spinal and epidural anesthesia recorded by an anesthesia information management system. *Anesthesiology* 2003;99(4):859-66.

Kim AJ, Kuroda MM, Nordli DR Jr. Abruptly attenuated terminal ictal pattern in pediatrics. *J Clin Neurophysiol* 2006;23(6):532-550.

Kuroda MM, Weck ME, Sarwark JF, Hamidullah A, Wainwright MS. Association of apolipoprotein E genotype and cerebral palsy in children. *Pediatrics* 2007;119(2):306-13).

Book chapter

Kuroda MM. Principles of Statistical Methods for Research in Regional Anesthesia. In: Textbook of Regional Anesthesia and Acute Pain Management. A Hadzic (ed.), McGraw Hill, New York, NY, 2007, pp1189-1215.

Invited lectures

Kuroda MM. The epidemiology of cerebral palsy. Instructional Course. United Cerebral Palsy (UCP Manhattan). New York, NY. September 22, 1999.

Kuroda MM. The role of the epidemiologist in the care of children with epilepsy. Chicago Public Schools Conference. Chicago, IL. February 22, 2003.

Kuroda MM. Birth asphyxia as a cause of cerebral palsy: "O what a tangled web we weave." Preventive Medicine Seminar, The Feinberg School of Medicine, Northwestern University. Chicago, IL. February 24, 2003.

Kuroda MM, Wainwright MS. The apolipoprotein E ϵ 4 allele in children with cerebral palsy. CMIER CRIB Retreat. Chicago, IL. March 14, 2003.

Kuroda MM, Buchanan LS, Zelko FA. Outcomes in childhood epilepsy: Assessment of health-related quality of life (HRQOL). CMIER CHR Science Meeting. Chicago, IL. September 23, 2003.

Kuroda MM. Basics of statistics: What an anesthesiologist needs to know. Visiting Professor, University of Miami, School of Medicine, Miami, FL. November 13, 2003.

Kuroda MM. Basics of statistics: What an anesthesiologist needs to know. Visiting Professor, St. Luke's-Roosevelt Hospital Center, New York, NY. September 27-28, 2005.

C. Research Support.

Outcomes in childhood epilepsy: Assessment of health-related quality of life (HRQOL), Shire US, Inc., Principal Investigator.

This study has been recently extended to assess the validity of the Quality of Life in Childhood Epilepsy (QOLCE) questionnaire as an indicator of outcome in an American population of children with intractable epilepsy. QOLCE subscales are correlated with behavior, emotionality, adaptive functioning, and impact of epilepsy on the child and family. Differences in QOLCE are tested by age at diagnosis, presence of co-occurring conditions, and ease of seizure control.

The apolipoprotein E ϵ 4 allele in children with cerebral palsy (CP), CMIER Seed Grant Program for New Ideas in Research, Principal Investigator.

The APOE alleles vary in their neuronal regenerative behavior. This pilot study evaluated the APOE allele distribution in children with CP seen by the Rehabilitation Division at CMH and tested the hypotheses that the frequency of the ϵ 4 allele, in particular, is (a) higher in children with CP as compared to controls and population norms, and (b) higher in children with more severe CP than in children with mild or moderate CP.

The apolipoprotein E ϵ 4 allele in children with cerebral palsy (CP), United Cerebral Palsy, Principal Investigator.

This study extended the evaluation of ApoE polymorphism in children with CP by using general pediatric controls matched to cases by gender, ethnicity, and gestational age.

Identification and short-term outcome of neonates at risk for cerebral dysfunction, MRJBF, Principal Investigator.

This study evaluated associations among EEG, MRI, and clinical findings of neonates with encephalopathy for their individual and joint abilities to predict neurodevelopmental outcome at one year of age. Structured around a study of neonatal seizures, this project established integrated services between the NICU and the Division of Neurology.

Baclofen Efficacy and Safety Trials – A Multi-center Retrospective Chart Review of the Pediatric Population Using Oral Baclofen to Manage the Spasticity of Cerebral Palsy (BEST-CHART), Study Coordinator.

This study is a retrospective chart review of pediatric patients with cerebral palsy taking oral baclofen to treat their spasticity. The chart review is preparatory to an evaluation of the pharmacokinetics/pharmacodynamics of oral baclofen in order to identify a range of tolerable doses that is both safe and effective in reducing spasticity and that can be used in a larger scale randomized clinical trial to provide more definitive evidence of safety and efficacy in children with cerebral palsy.

BIOGRAPHICAL SKETCH

Provide the following information for the key personnel and other significant contributors in the order listed on Form Page 2.
Follow this format for each person. **DO NOT EXCEED FOUR PAGES.**

NAME Gaebler-Spira, Deborah J.		POSITION TITLE Professor, Department of Physical Medicine and Rehabilitation, Professor, Department of Pediatrics	
eRA COMMONS USER NAME DGAEBLER			
EDUCATION/TRAINING <i>(Begin with baccalaureate or other initial professional education, such as nursing, and include postdoctoral training.)</i>			
INSTITUTION AND LOCATION	DEGREE <i>(if applicable)</i>	YEAR(s)	FIELD OF STUDY
University of Illinois, Urbana	B.S.	1974	Zoology
University of Illinois, Chicago	M.D.	1979	Medicine
University of Illinois Hospital & Clinics, Chicago	Residency	1979-82	Pediatrics
Rehabilitation Institute of Chicago, Chicago	Residency	1982-85	PM&R
		2003	PRM (Pediatric Rehabilitation Medicine)

Positions and Employment:

2007 – present Professor, Department of Physical Medicine and Rehabilitation, Northwestern Feinberg School of Medicine - Pediatrics
 1987 – present Director, Cerebral Palsy/Spasticity Management Program, Rehabilitation Institute of Chicago
 1998 – 2007 Associate Professor, Department of Physical Medicine and Rehabilitation, Northwestern University Medical School
 1998 – present Clinic Chief, Pediatric Amputee Clinic, Rehabilitation Institute of Chicago
 2001 – 2007 Associate Professor, Department of Pediatrics, Northwestern University Medical School
 1985 – present Attending Physician, Pediatric and Adolescent Rehabilitation Program, Rehabilitation Institute of Chicago

Consultant:

1985 – present Children's Memorial Hospital, Chicago
 1986 – 1989 Larabida Children's Hospital and Research Center, Chicago
 1989 – present Chicago Board of Education, Chicago
 1992 – 1995 Condell Medical Center, Libertyville, Illinois
 1994 – 1996 University of Illinois Clinic/Adults with Cerebral Palsy, Chicago
 1998 – present Cook County Hospital, Chicago, Illinois
 2000 – 2004 Loyola University Medical Center, Maywood, Illinois

Other Experience and Professional Memberships

American Board of Physical Medicine and Rehabilitation: Steering Committee, Pediatric Rehabilitation Medicine, Fellowship: 1999-present; Associate Member of the Board: 2000 -present

American Academy of Physical Medicine & Rehabilitation:

Pediatric Rehabilitation Special Interest Group (SIG) Chairperson 1996-1998;

Liaison to the American Academy of Pediatrics National Committee on Children with Disability, 1993-1998

American Academy for Cerebral Palsy and Developmental Medicine:

Member, Adaptive Sports and Recreation Committee, 1991-present (Chairperson 1995-96),

Member, Board of Directors, 2000- 2004

Membership Committee, 1996-2000

Program committee 2002-2003

Instructional Course Chairperson 2003-2004

American Academy of Pediatrics 1985-present

Principal Investigator/Program Director (Last, First, Middle): Gaebler-Spira, Debra J

Illinois Chapter, American Academy of Pediatrics, Committee on Children with Disabilities, March 1995-present
Section Membership, Chronic Illness & Disability, American Academy of Pediatrics, 1992-present
Academy of Pediatrics, Committee on Children with Disabilities, 1993-1998 liaison
Medical Advisory Committee, Easter Seal Society of Metropolitan Chicago, 1992 – present
Professional Advisory Board, United Cerebral Palsy, June 1991-present
Pathways Awareness Foundation 1990-present
Steering Committee; Advisory for the Rehabilitation Institute of Chicago in Prosthetics and Orthotics 1998-2000
NIH Taskforce on Childhood Hypertonia: 1999 to present
The United Cerebral Palsy Research and Educational Foundation Isabelle and Leonard H. Goldenson
Technology and Rehabilitation Science Award, 2005

B. Selected peer-reviewed publications (in chronological order).

Marty G, Dias L, Gaebler-Spira D: Selective posterior rhizotomy and soft-tissue procedures for the treatment of cerebral diplegia. *Journal of Bone and Joint Surgery*; Vol 77A, May 1995

Richter KJ, Gaebler-Spira D, Adams Mushett C: Sports and the person with spasticity of cerebral origin. *Devel Med & Child Neurol*; AACPDM Vol 1996;38/9:867-870

Gaebler-Spira D: Committee on Children with Disabilities: the role of the pediatrician in prescribing therapy services for children with motor disabilities. *Pediatrics* 1996;98:308-310

Gaebler-Spira D: The use of Botulinum toxin in children: a retrospective study of adverse reactions and treatment of idiopathic toe walking. *European Journal of Neurology* 1997, 4 (suppl 2): S27-30

Graham H, Aoki R, Autti-Ramo, Gaebler-Spira D: Recommendations for the use of toxin type A in the management of cerebral palsy. *Gait Posture* 11/2000; pp 67-69

Gormley M, Gaebler-Spira D, Delgado M: The use of Botulinum toxin type-A in pediatric patients with cerebral palsy: A three-center retrospective chart review. *Journal of Child Neurology*, February 2001

Garcia RA, Gaebler-Spira D, Sisung C, Heinemann AW: "Functional Improvement after Pediatric Spinal Cord Injury". *Am J Phys Med Rehabil.* 2002; 81(6): 458-63.

Schneider J, Gutierrez, A, Gaebler-Spira, D: Health-Related Quality of Life and Functional Outcome Measures for Children with Cerebral Palsy. *Developmental Medicine & Child Neurology* 2001; 43:601-608

Yasukawa A, Malas B, Gaebler-Spira D: "Efficacy for Maintenance of Elbow Range of Motion of Two Types of Orthotic Devices: A Case Series." *JPO Journal of Prosthetics and Orthotics* 2002; 15(2): 72-77.

Sanger TD, Delgado MR, Gaebler-Spira D, Hallett M, Mink JW; Task Force on Childhood Motor: "Disorders. Classification and definition of disorders causing Hypertonia in childhood." *Pediatrics.* 2003; 111(1):e89-97.

Gaebler-Spira D, Revivo, G: "The use of Botulinum Toxin in Pediatric Disorders" *Physical Medicine Rehabilitation Clinical. N. Am.* 2003; 14:703-725

Schmidt B, Gaebler-Spira D: "Mechanical Measurements of the Effects of Intrathecal Baclofen Dosage Adjustments in Cerebral Palsy – A Pilot Study". *Am. Journal of Med. Rehabilitation* 2004; 83(1):33-41

Lebiedowska MK, Gaebler-Spira D, Burns RS, Fisk JR. "Bio-mechanic Characteristics of Patients with Spastic and Dystonic Hypertonia in Cerebral Palsy". *Archives of Physical Medicine and Rehabilitation* 2004; 85(6): 875-881

Kamper, D, Yasukawa A, Barrett K, Gaebler-Spira D. "Effects of Neuromuscular Electrical Stimulation Treatment of Cerebral Palsy on Potential Impairment". *Pediatric Physical Therapy*, Spring 2006; 18(1): 31-38.

Sanger T, Chen D, Delgado M, Gaebler-Spira D, Hallett M, Mink J, The Taskforce on Childhood Motor Disorders. "Definition and Classification of Negative Motor Signs in Childhood" *Pediatrics*, November 2006; 118(1): 2159-2167.

Bourke-Taylor H, O'Shea R, Gaebler-Spira D. "Conductive Education: A Functional Skills Program for Children with Cerebral Palsy". *Physical & Occupational Therapy in Pediatrics* 2007; 27:45-62

C. Research Support

ONGOING

RFP-NIH-NICHD-2005-13 (Brunstrom) 05/15/06-09/14/11

NICHD

Best Pharmaceuticals for Children Act Pediatric Drug Study: Use of Oral Baclofen for Treatment of Spasticity of Cerebral Palsy in Children

Subcontract from Washington University in St. Louis

The major goals of the project are to develop pharmacokinetic and pharmacodynamic parameters of oral baclofen use in children with cerebral palsy, establish efficacy and safety.

Role: Co-Investigator

(Campbell) 01/01/07 -01/31/08

UIC CTSA Research Initiative Pilot Grant Program

A Clinical Trial of Early Physical Therapy to Promote Development of Locomotion in Infants with White Matter Injury

The major goals of the project are to determine if early institution of a kicking program improves ambulation and effect on diagnosis of CP.

Role: Co-Investigator

(Zhang) 03/01/05-08/31/07

Stanford University

Intelligent Stretching and Outcome Evaluation of Spastic Ankles in Children with CP

The major goals of the project are to treat children with CP and spastic ankle using a novel device and evaluate the outcome in terms of both biomechanical and reflex properties

Role: Co-Investigator

(Damiano) 10/01/06-09/30/07

AACPDM

AACPDM Research Group Project: Evaluating Outcomes Associated with Multidisciplinary Care for Children with Cerebral Palsy Using Clinical Practice Improvement (CPI) Methodology

The specific aim of this planning grant is to organize a group of multidisciplinary clinical investigators from centers that specialize in the care of children with CP, all of whom are active members of the AACPDM to submit a multidisciplinary and multicenter grant proposal on the use of CPI methodology to evaluate clinical outcomes for children with CP associated with specific types of interventions and patient characteristics.

Role: Investigator

Completed Research Support

5 R01 NS43143-04 (Damiano)

07/01/03 – 06/30/06

NIH/NINDS

Effects of Baclofen on Muscle Strength in Cerebral Palsy

The specific aims of this project are to quantify the changes in torque production, spasticity and selective control as a result of intrathecal baclofen therapy in spastic cerebral palsy and to determine the interplay of these clinical changes on functional motor outcomes so as to improve clinical applications of this therapy in cerebral palsy.

Role: Co-Investigator

R-746-03 (Gaebler-Spira)

07/01/03 – 12/31/05

United Cerebral Palsy Research & Educational Foundation

Randomized, Double-Masked, Placebo-Controlled Study of Upper Extremity Function with Botulinum Toxin A

The goal of this study was to provide evidence that Botulinum Toxin A injection is an effective method to treat spasticity affecting upper extremity function in children with cerebral palsy.

Role: PI

R-736-02 (Sanger)

01/01/02 – 12/31/04

UCPF Stanford University

Childhood Hypertonia of Cerebral Origin: An Open-Label Trial of Trihexphenidyl (Trihexyphenidyl) Treatment Effects

The goals of this multi-center prospective open-label study of trihexyphenidyl in children with upper and lower extremity dystonic hypertonia due to static encephalopathy were to validate these findings in a larger sample with a more objective and comprehensive set of outcome measures, and to provide further support for proceeding to a randomized clinical trial.

Role: Co-Investigator

(Gaebler-Spira)

10/01/02-12/31/05

Medtronic

Energy Expenditure, Nutritional Status and Quality of Life in Children with Spasticity who Undergo Intrathecal Baclofen Treatment

The aim of this pilot project is to determine the impact of intrathecal baclofen treatment on energy balance, growth, nutritional status and quality of life in children with spasticity.

Role: PI

To test the hypothesis that psychosocial functioning is lower in children with surgical resection of *congenital* epileptogenic lesions than in children with resected *acquired* nonepileptogenic tumors.

Children with epilepsy are at elevated risk for psychological disturbance, social maladjustment, and adaptive skills limitations. Long-term prospective studies indicate that children with epilepsy are also at greater risk for failure to meet educational, vocational, and social goals. Such findings suggest that a chronic childhood illness such as epilepsy, manifesting during a period of substantial psychosocial growth, can give rise to a number of problems with far-reaching effects. Abnormal electrical discharges from epileptogenic lesions may contribute to these outcomes if the plasticity of the immature nervous system mediates atypical development in response to such insults. The current study proposes that patients with resected lesions are an appropriate group in which to study these effects. Thus adaptive skills, behavior, emotionality, and quality of life were compared between children who had undergone brain surgery for congenital (presumably co-natal) lesions that were epileptogenic versus acquired (presumably more recently developed) tumors that were not epileptogenic.

Ten Epilepsy Center patients with active presurgical interictal epileptiform discharges were matched on age at time of surgery with 10 patients from the Division of Neurosurgery with low-grade supratentorial tumors. The tumors were comparable to the epileptogenic lesions in gray matter involvement and had not spread to require radiation or chemotherapy. Adaptive skills were sampled using the Woodcock-Johnson Scales of Independent Behavior, administered by phone. Parents also rated their child's quality of family life, general health, behavior, emotions, social interactions, and school performance. The Child Behavior Checklist (CBCL), a longer parent survey of behavioral and emotional symptomatology, was completed by mail.

Adaptive skills were lower in children with epilepsy than children with tumors (standard scores $86 + 38$ v $113 + 21$, respectively, $p < 0.025$). Total CBCL scores were clinically significant for 4 children with epilepsy but only 1 with a tumor; both internalizing and externalizing symptomatology appeared to be elevated in children with epilepsy. While general health and the family's overall quality of life were similar between groups, overall quality of life tended to be lower for the child with epilepsy, as were behavior and social functioning. All children with tumors did satisfactory work or better in school, however several children with epilepsy did unsatisfactory work in language-based academics and mathematics.

Matching on age at time of surgery was the only feasible control for developmental age given the small number of surgical patients with epilepsy in this new Epilepsy Center. With this caveat, children with epilepsy appear to be at risk for detrimental effects on adaptive skills, behavior-emotionality, and social functioning. Further studies are needed in order to establish the disruptive effects of electrophysiological insult on psychosocial and cognitive development in childhood epilepsy.