

BIOGRAPHICAL SKETCH

Provide the following information for the Senior/key personnel and other significant contributors.
 Follow this format for each person. **DO NOT EXCEED FIVE PAGES.**

NAME: Deborah J. Gaebler-Spira

eRA COMMONS USER NAME (credential, e.g., agency login):

POSITION TITLE: Professor

EDUCATION/TRAINING *(Begin with baccalaureate or other initial professional education, such as nursing, include postdoctoral training and residency training if applicable. Add/delete rows as necessary.)*

INSTITUTION AND LOCATION	DEGREE <i>(if applicable)</i>	Completion Date MM/YYYY	FIELD OF STUDY
University of Illinois, Urbana, IL	BS	1975	Zoology
University of Illinois, Chicago, IL	MD	1979	Medicine
University of Illinois Hospital & Clinics, Chicago, IL	Residency	1979-82	Pediatrics
Rehabilitation Institute of Chicago, Chicago, IL	Residency	1982-85	Phys Med & Rehab

A. Personal Statement

I have been working with children and young adults with cerebral palsy in a multidisciplinary team at Shirley Ryan AbilityLab (formerly RIC) for over 30 years. I have collaborated in the past with clinicians as well as the researchers at Shirley Ryan AbilityLab on robotic innovations to improve gait, trunk control and impairments that impact children with cerebral palsy. We have developed a close collaboration. I have a robust clinical population and many contacts that will assist with the recruitment strategies to insure success. I have had opportunities to work at the national level and international level of defining and creating objective outcomes for children with CP.

B. Positions and Honors

Positions

- 1985-present Attending Physician, Pediatric and Adolescent Rehabilitation Program, Shirley Ryan Ability (Formerly Rehabilitation Institute of Chicago)
- 1998-present Clinic Chief, Pediatric Amputee Clinic, Rehabilitation Institute of Chicago
- 2007-present Professor, Northwestern Feinberg School of Medicine Department of Physical Medicine and Rehabilitation and Pediatrics

Consultant

- 1985-present Ann and Robert H. Lurie Children’s Hospital, Chicago
- 1994-1996 University of Illinois Clinic/Adults with Cerebral Palsy, Chicago

Honors

- 2018 AACPDM Lifetime Achievement Award
- 2013 Pioneer Award – Pathways.org
- 2005 Isabella and Leonard Goldenson Technology and Rehabilitation Award, United Cerebral Palsy Foundation.

Other Experience and Professional Memberships

- 1990-present Pathways Awareness Foundation
- 2016-present Cerebral Palsy Foundation, Cerebral Palsy International Research Scientific Advisory Board
- 1991-present Cerebral Palsy Foundation, Cerebral Palsy International Research Professional Advisory Board

1996-1998	American Academy of Physical Medicine & Rehabilitation (AAPMR) Think Tank Pediatric Visioning Pediatric Rehabilitation Special Interest Group (SIG) Chairperson
2014	AAPRM Awards Committee
1999-2010	NIH Taskforce on Childhood Hypertonia
1992-present	American Academy of Pediatrics (AAP) Section Membership, Chronic Illness & Disability
1995-1998	AAP National Committee on Children with Disability Liaison
1995-present	AAP Illinois Chapter, Committee on Children with Disabilities (Co-Chairperson 2011-2013)
1999-2008	American Board of Physical Medicine and Rehabilitation Steering Committee, Pediatric Rehabilitation Medicine Fellowship
1999-2008	American Board of Physical Medicine and Rehabilitation Associate Member of the Board
1999-2002	American Academy for Cerebral Palsy and Developmental Medicine (AAPDM Member, Board of Directors
2002-2003	AAPDM Program Committee
2003-2004	AAPDM Instructional Course Chairperson
2009-2010	AAPDM President
2015	AAPDM Editorial Board - Developmental Medicine and Child Neurology
2017	AAPDM Publication Committee Chair

C. Contributions to Science

1. My contribution to science has been primarily in multi center collaborative projects related to cerebral palsy. I was an organizing member of the NIH task force for childhood motor disorders. The task force led an effort to unify the language and to provide definition and objective measurement of the key impairments found in cp. This important work was led by neurologist and pediatric neurologist and had major impact on the field of cerebral palsy research. The inclusion of pediatric Physical Medicine & Rehabilitation broadened the approach to consider function. The following papers were a direct result of the taskforce.
 - a. Sanger T, Bastian A, Brunstrom J, Damiano D, Delgado M, Dure L, Gaebler-Spira D, Hoon A, Mink J, Sherman-Levine S, Welty L, The Child Motor Study Group. "Prospective Open-Label Clinical Trial of Trihexyphenidyl in Children with Secondary Dystonia due to Cerebral Palsy", *J Child Neurol*, 2007; 22: 530. PMID: 17690057
 - b. 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. PMID: 17079590
 - c. Lebedowska M, Gaebler-Spira D, Burns R, Fish J. "Biomechanic Characteristics of Patients with Spastic and Dystonic Hypertonia in Cerebral Palsy". *Arch Phys. Med. Rehabil.* June 2004; 85: 875-880. PMID: 15179639
 - d. Sanger T, Delgado M, Gaebler-Spira D, Hallett M, Mink J. "Classification and Definition of Disorders Causing Hypertonia in Childhood." *Pediatrics*, January 2003; 111(1): 89-97. PMID: 12509602

2. As a result of the NIH taskforce effort, I began to collaborate with the bioengineers at RIC. Dr Zhang assisted and I worked on multiple projects that utilized robotic ankle devices that measured aspects of impairment. In utilizing the robotics for measurement, a treatment paradigm was developed to engage children in a self-stretching program. This has been a very active area of research. The publications are important as they demonstrate a potential telerehab experience for treatment. In addition, the mechanism of contracture has begun to be unraveled. Other collaborative efforts include work with Dr. Jules Dewald at Northwestern University School of Physical Therapy and with Dr. Ming Wu on a treadmill training device as well as a robotic horse.
 - a. Sukal-Moulton T, Clancy T, Zhang LQ, Gaebler-Spira D. Clinical application of a robotic ankle training program for cerebral palsy compared to the research laboratory application: does it translate to practice? *Arch Phys Med Rehabil.* 2014 Aug;95(8):1433-40. doi: 10.1016/j.apmr.2014.04.010. PMID: 24792141
 - b. Sukal-Moulton T, Krossschell K, Gaebler-Spira D, Dewald J. Motor impairment related to brain injury timing in early hemiparesis Part I: expression of upper extremity weakness. *Neurorehabil Neural Repair.* PMID: 24009182

- c. Sukal-Moulton T, Krossschell KJ, Gaebler-Spira D, Dewald JPA. Motor impairment related to brain injury timing in early hemiparesis Part II: abnormal upper extremity joint torque synergies. *Neurorehabil Neural Repair*. PMID: 23911972
 - d. Wu YN, Hwang M, Ren Y, Gaebler-Spira D, Zhang LQ. Combined Passive Stretching and Active Movement Rehabilitation of Lower-Limb Impairments in Children With Cerebral Palsy Using a Portable Robot. *Neurorehabil Neural Repair*. 2011 Feb 28. PMID: 21343525
3. Intervention trials for children with cerebral palsy are rare but another collaborative effort involved the department of physical therapy at the University of Illinois with Dr. Suzanne Campbell et al more common are the drug trials. Oral medications have been used in children without many clinical trials. I have participated in 2 major trials of medication and have been one of the highest recruiters for each study. The involvement with the pediatric off label drug study, another NIH oral medication trial demonstrates my ability to work with a large group and recruit patients. Attention to excellence in clinical care within the research bounds has been consistent in my practice of medicine and my participation in research.
 - a. He Y, Brunstrom-Hernandez JE, Thio LL, Lackey S, Gaebler-Spira D, Kuroda MM, Stashinko E, Hoon AH, Vargus-Adams J, Stevenson RD, Lowenhaupt S, McLaughlin JF, Christensen A, Dosa NP, Butler M, Schwabe A, Lopez C, Roge D, Kennedy D, Tilton AH, Krach LE, Lewandowski A, Jusko WJ. Population Pharmacokinetic Analysis of Oral Baclofen in Pediatric Patients with Cerebral Palsy. *J. Pediatr*. 2014 Mar 4. pii: S0022-3476(14)00057-2. doi: 10.1016/j.jpeds.2014.01.029. PMID: 24607242
 4. Another contribution to research is as a partner in the development and the promotion of the cerebral palsy research registry. Though cerebral palsy is the most common motor disability of childhood, there is no national registry or database to promote research, recruitment or retention of longitudinal data. The need for a registry is critical as children and adults with cerebral palsy have lifelong needs and increased utilization of health care and related services.
 - a. Hurley DS, Sukal-Moulton T, Msall ME, Gaebler-Spira D, Krossschell KJ, Dewald JP. The Cerebral Palsy Research Registry: Development and Progress Toward National Collaboration in the United States. *J Child Neurol* Volume 26 Issue 12: December 2011 pp. 1534 - 1541. PMID: 21677201

Complete List of Published Work in MyBibliography:

<http://www.ncbi.nlm.nih.gov/sites/myncbi/1JiK8ISqTLq5k/bibliography/47777913/public/?sort=date&direction=ascending>.

D. Additional Information: Research Support and/or Scholastic Performance

Ongoing Research Support

AACPDM Theresa Sukal Moulton 9/1/19 – 12/31/20
 RaceRunning for fitness in an elementary school setting: pilot testing and program development
 The goal of the study is to determine the effect of an exercise program on cardiovascular fitness
 Role: Consultant

AACPDM (Pedal with Pete Foundation) Dizon (PI) 12/31/19 – 12/31/20
 Identifying Mechanisms for the Neuroprotective Effects of Intrapartum Magnesium
 Role: Co-Investigator.

NIDILRR Kuiken (PI) 1/10/18 – 9/30/23
 TEAMM-RERC. Customized Therapeutic Intervention for Cerebral Palsy: A Child-Specific Robotic Trainer
 Role: Co-Investigator

CIHR Wright (PI) 1/13/16-12/31/20
 Evaluation of the effectiveness of robotic gait training and gait focused physical therapy programs for children with cerebral palsy a mixed methods RCT
 The goal of the RCT is to compare: 1) Lokomat (LOK) program, 2) functional physical therapy program (FPT) that includes activities to enhance balance/co-ordination/endurance and advanced motor skills conducted on

'real ground', 3) an integrated Lokomat + functional physical therapy (LOK+FPT), and 4) a wait-list control condition (CONT) for children and youth with CP (GMFCS levels II and III, ages 5-18y)

Role: Site PI

[2R01NS063399-06](#) NIH

Kording (PI)

4/1/15 3/31/20

The Role of Uncertainty for motor learning and adaptation

The goal is to use experiments with human subjects and model building to quantify the role of learning for the processing of uncertainty.

Role: Co-Investigator

Completed Research Support

Allergan

Mukherjee (PI)

8/13/12 – 12/31/217

BOTOX Treatment of Pediatric Lower Limb Spasticity Open-Label Study

The goal of the study is to evaluate the safety and effectiveness of botulinum toxin for equinus gait in children with cerebral palsy.

Role: Co-Investigator

Allergan

Mukherjee (PI)

8/13/12 - 10/31/16

BOTOX Treatment of Pediatric Lower Limb Spasticity Double-Blind Study

The goal of the study is to evaluate the safety and effectiveness of botulinum toxin for equinus gait in children with cerebral palsy.

Role: Co-Investigator

Holland Bloorview Kids Rehabilitation Hospital King(PI)

2/26/15-9/30/16

"Engagement in the Pediatric Rehabilitation Intervention Process: Its Nature, Measurement, and Role in the Determination of Outcomes"

The goal is to improve understanding of the principals of parent and child engagement and how this effects outcomes in rehabilitation.

Role: Co-Investigator for RIC

CPIRF

Gaebler(PI)

3/15/15-3/14/16

Transforming Healthcare for Women with Disabilities

The goal is to determine and reduce barriers to reproductive health and mammography for women with cp.

Merz Pharmaceuticals Gmbh

Gaebler (PI)

9/12/14 - 2/1/216

Prospective, multicenter, randomized, double-blind, parallel-group, dose-response study of three doses Xeomin® (incobotulinumtoxinA, NT 201) for the treatment of upper limb spasticity alone or combined upper and lower limb spasticity in children and adolescents (age 2 - 17 years) with cerebral palsy

The goal is to investigate the safety and efficacy of Xeomin in subjects with upper limb spasticity or both upper limb and lower limb spasticity due to cp.

RERC NIDDIR

Zhang (PI)

9/30/11 – 8/31/16

"Research Center on Technologies for Children with Orthopedic Disabilities"

The goal of the projects are to assess and develop robotics to enhance function in children with CP for gait.

Role: Co-PI for RIC

CNS

Gaebler (PI)

5/10/12 – 7/31/16

Study to Assess the Safety of 3 mg/mL Gablofen® (baclofen injection) Delivered by Intrathecal Administration Using the SynchroMed® II Programmable Infusion System (CNS-GAB101US)". Clinical Trial

The goal of this study is to evaluate the safety of 3000mcg concentration of gablofen for intrathecal drug delivery for spasticity in children and adults with cerebral palsy.

Ultraflex Systems Inc. Gaebler-Spira (PI) 01/09/12 – 8/31/15

“Pilot Study: Effect of Two Orthotic Approaches to Ankle Motion Restriction on Activity Level, Balance and Patient Satisfaction in Children with Cerebral Palsy”

The purpose of this project is to evaluate whether the approach to orthotic management and degree of ankle motion restriction affect activity level, balance and satisfaction in children with CP.

Role: Co-Investigator

RERC NIDDR #H133E100007A Gerald Harns (PI) 10/1/10 - 9/30/15

Research Center on Technologies for Children with Orthopedic Disabilities (subK flow through Marquette)

Goal of the projects are to assess and develop robotics to enhance function in children with CP for gait.

Role: Co-PI for RIC

R-812-13

Wu (PI)

9/1/13 - 8/31/15

Cerebral Palsy International Research Foundation

Robotic Pelvis Manipulation Improves Dynamic Balance and Walking in Children with Cerebral Palsy.

The goal of the study is to examine the effectiveness of a robotic horse movement on posture and balance in children with cerebral palsy.

Role: Co-Investigator

CPIR Lopez-Ortiz (PI) 12/31/12-12/31/14

“Dance for Motor Learning in Children with Cerebral Palsy”

Goal of the study is to understand motor segmentation and motor learning in children with cerebral palsy using classical dance training.

Role: Co-PI

AACPDM Clinical Research

Zhang (PI)

4/1/13 - 12/31/14

Pilot Multi-Center Evaluations of Reflex and Non-reflex Changes in Cerebral Palsy Using a Portable Device.

The goal of this project is to develop the portable neuromechanical device to evaluate hypertonia in children with CP.

Role: Co-PI

1R21HD066261

Wu (PI)

8/1/11-7/31/14

NIH

Robotic Gait Training Improved Locomotor Function in Children with Cerebral Palsy

The goal of this study is to improve the efficacy of body weight supported treadmill training in children with cerebral palsy using a novel robotic therapy that applies controlled forces to the leg during the swing phase of gait.

Role: Co-Investigator

#OPERF-2012-SGA-1 Fatone & Pavone (Co-PIs) 05/01/12 – 04/30/13

Orthotic and Prosthetic Education & Research Foundation (OPERF)

“Improving Lower Extremity Orthotic Management of Children with Cerebral Palsy”

The purpose of this project is to demonstrate that ankle-foot orthoses-footwear combinations (AFO-FCs) improve knee and hip kinematics and kinetics during walking to a greater extent than ‘conventional’ AFOs, leading to improved balance, step length, walking speed, and self-reported function, and that these improvements increase with time.

Role: Co-Investigator