

2007 CHARGE Syndrome Foundation Professional Board Meeting
Thursday, July 26, 2007, 2:00-6:00, Bristol Room 3, Hilton Costa Mesa Hotel, Costa Mesa, CA

LIST OF PARTICIPANTS

CHARGE Foundation Research Committee Chair

Meg HEFNER, M.S.

Genetic Counselor and Clinical Associate Professor of Pediatrics, Saint Louis University School of Medicine
ADDRESS: FETU/Genetics, St. Mary's Health Center, 6420 Clayton Rd, St. Louis, MO 63117
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Meg has been a genetic counselor for 27 years, 24 of those working on CHARGE syndrome..

She wrote the original Booklet for Families with Sandra Davenport and Jim Thelin and co-wrote and co-edited the Management Manual for Parents. Meg was a founding member of the CHARGE Syndrome Foundation Board of directors and coordinated the first several International conferences. She continues as a Special Advisor to the Board, Chair of the Research Committee and presenter at conferences. She was a guest editor of the American Journal of Medical Genetics special issue on CHARGE syndrome. She has been an invited speaker on CHARGE syndrome to professional and lay audiences around the world. In addition to her work with CHARGE syndrome, she is a prenatal genetic counselor.

CHARGE Foundation Professional Board Chair

James W. THELIN, Ph.D.

Vice President, CHARGE Syndrome Foundation; Associate Professor of Audiology, University of Tennessee.
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Jim Thelin is an audiologist who teaches graduate students at the U of Tennessee. He has been active in CHARGE since the early 1980's. His research initially focused on hearing in CHARGE, but he is now studying the factors that affect communication development and the relationship between mobility and the acquisition of symbolic language. His research has been conducted in collaboration with professionals and students at the U of Missouri School of Medicine and the U of Tennessee.

Professional Board Meeting Participants

Maurice BELOTE

Project Coordinator, California Deaf-Blind Services

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Maurice Belote has served on the staff of California Deaf-Blind Services since 1992, and has been the CDBS Project Coordinator for ten years. His experience with students with CHARGE Syndrome began in 1981 during his second week as a teaching intern at the California School for the Blind. Since completing the teacher training program in deaf-blindness at San Francisco State University, Mr. Belote has taught at public and private schools throughout California, and has developed innovative models at local school sites related to integration into general education programs, augmentative and alternative communication systems, community-based instruction, job training, and transition from school to supported living and employment.

Donna D. BENT

Orientation and Mobility Specialist in Perkins Deafblind program for 21 years; classroom teacher in deafblind program and works in the Perkins Low Vision Clinic

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MA Boston College (Orientation and Mobility); CAGS Boston College (Vision Handicaps); MS Wheelock College (Early Childhood Education)

Jorieke BERGMAN, MD

Clinical geneticist in training and PhD-student

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After completing medical school I began with specializing in Clinical Genetics at the University Medical Center Groningen. From the beginning I was very interested in CHARGE syndrome. I was very lucky to receive a grant, which allows me to start with a PhD project on this subject. I intend to study the overlap between CHARGE syndrome and Kallmann syndrome. Kallmann syndrome is characterized by hypogonadotropic hypogonadism (absent puberty) and anosmia (inability to smell) and these two features are also frequently present in CHARGE syndrome. In addition to clinical studies in CHARGE and Kallmann patients, I will also perform mouse studies in the Wellcome Trust Sanger Institute in Cambridge, Great Britain. I hope that the mouse studies will help me to understand the relationship between CHD7 (the gene involved in CHARGE syndrome) and the genes that are involved in Kallmann syndrome.

Dr. Veronika BERNSTEIN

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Dr. Bernstein's training is in the brain and behavior field with the post-doctoral in child Neuropsychology at the Harvard Medical School. She has been working in the field for about 35 years, the last 20 years at the Perkins School for the Blind, Watertown, MA. Dr. Bernstein has been involved in education of children with CHARGE for the past 20 years. Her presentations and trainings nation-wide and abroad are focused on Repetitive Behaviors, Autistic-like Behaviors in Children with Sensory Impairments, Hormonal and Sleep Disorders and other issues of concern to families and educators of children with CHARGE.

Kim BLAKE, M.D.

General Pediatrician, Associate Dean University Medical Education, Dalhousie University

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Dr. Kim Blake began her involvement with CHARGE more than 25 years ago at Great Ormand Street Hospital in the UK, where she lectured on CHARGE and published several of the earliest papers describing the syndrome. She was instrumental in organizing the UK family support group. Since moving to Canada, she has continued to be involved with the CHARGE Syndrome Foundation. She has been an invited speaker at every conference and received funding from the Foundation for several of her research projects. In 2005, Kim was awarded a "Stars in CHARGE" for her dedication and work with families, parents and professionals. Her research career continues to focus on CHARGE, particularly the issues of the adolescent and adult population. She routinely involves students in her research, both educational and clinical. Most of her students have had abstracts and/or papers published, some even with first authorship. Kim has recruited many local medical faculty in her research and developed quite a center of excellence for research and knowledge in CHARGE syndrome. She is regularly asked to present on CHARGE syndrome, both nationally and internationally. Her most recent research projects are on the effects of anesthesia in CHARGE syndrome and the feeding difficulties in children with CHARGE syndrome.

Elizabeth A. BREADON, PT., DPT.

Physical Therapist , Perkins School for the Blind

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Elizabeth (Liz) Breadon PT., DPT. is a physical therapist at Perkins School for the Blind in Watertown, MA. She received a BSc. Physiotherapy from the University of Ulster, Northern Ireland and her Doctor of Physical Therapy from Simmons College Boston in 2005. Liz is NDT certified therapist and has 25 year experience working in adult and pediatric rehabilitation. Liz has worked at Perkins School for the Blind for nine years where she gained extensive experience working with children with CHARGE. She has a particular interest in the orthopedic anomalies in CHARGE and in developing treatment strategies to compensate for vestibular anomalies in CHARGE.

David BROWN

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David has been working with children and young adults with CHARGE Syndrome since 1982, in his role as a specialist deaf-blind teacher. He has a special interest in the topics of assessment, sensory systems, and the interface between therapy and education.

Donna CONSACRO, BA

Family Services Coordinator, Tennessee Deafblind Project

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Donna Consacro has worked as the Family Services Coordinator for TRENDS (Tennessee Deafblind Project) for 14 years. She is the mother of an adult daughter who was born profoundly deaf and grandmother of twin granddaughters who are profoundly deaf. Donna works with the families of children on the Tennessee Deafblind Census to assist them with locating a variety of resources and information to support to their children.

Nancy CORNELIUS

National Family Association Board Member, Region 9;

Program Assistant for the Deaf/Hard of Hearing Infant Program, San Diego Unified School District

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I am the parent of a twenty-one year old daughter, Amy who has CHARGE Syndrome. I am the National Family Association for Deaf-Blind Board Member representing Region 9. I was a staff member with California Deaf-Blind Services for nine years. I continue to sit on the Advisory Committee for California Deaf-Blind Services. I am an officer for the Coalition of Parents and Educator, Deaf-Blind in California. I am the Program Assistant for the Deaf/Hard of Hearing Infant Program for San Diego Unified School District.

Sandra L.H. DAVENPORT, M.D.

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Dr. Sandra Davenport is a Pediatric Geneticist and Developmental Pediatrician who specializes in sensory losses. She has a private consulting practice called Sensory Genetics/Neuro-development. She is currently a consultant to the Minnesota DeafBlind Technical Assistance Project and has been on its Advisory Council for 15 years and is also member of the Early Hearing Detection & Intervention and Newborn Screening committees through the Minnesota Department of Health. She has also been the President and Board Member of SENTAC (the Society for Ear, Nose and Throat Advances in Children). Dr. Davenport was the chairman for two years of the Usher Consortium, a group of geneticists who were searching for the Usher genes and was involved in the research that led up to finding two of these genes. She was also a founding member of the CHARGE Syndrome Foundation board and is the co-author/editor of the original and updated CHARGE Manual for Parents and Professionals. For six years she directed the Vision Screening Project, a federally funded grant which helped identify students with dual sensory loss among those in deaf and hard-of-hearing programs in Minnesota and North Dakota.

Maryann M. GIRARDI, PT, DPT, ATP

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I am a physical therapist who is currently working in the Deafblind Program at Perkins School for the blind. I have worked with deafblind individuals for over 15 years. I primarily work with students to improve their gross motor, balance and mobility skills. In doing this I have developed a nontraditional approach to treatment using functional activities to increase strength and balance. I have recently completed my clinical doctorate in physical therapy. My studies included a research project on modifying standardized gross motor testing to accommodate visual impairments for children with CHARGE Syndrome. It demonstrated that the children were able to obtain higher level skills with the visual modifications. I have an interest in the musculoskeletal component of CHARGE Syndrome and I am currently researching foot anomalies.

Joshua K. HARTSHORNE

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Joshua Hartshorne is an entering graduate student in psychology at Harvard University. He has a brother with CHARGE. He has attended several CHARGE conferences in the past.

Dr. Nancy Salem HARTSHORNE

Professor, Department of Psychology, Central Michigan University
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Nancy Hartshorne is a professor at Central Michigan University, a School Psychologist, and a program consultant. She is co-author of numerous articles and book chapters pertaining to CHARGE syndrome, inclusion strategies and tools. Her son, Jacob, age 15, was fully included throughout his elementary school years. He has experienced successful transition into a progressively more and more inclusive high school experience. Jacob is deafblind and has significant developmental delays as a result of CHARGE syndrome. Nancy is an advocate for teamwork, thorough planning, and forward thinking for a quality education in the least restrictive environment for all children.

Tim Hartshorne, Ph.D.

Professor of Psychology
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Tim is a professor of psychology at Central Michigan University. He is also the father of an 18-year-old son with CHARGE. Tim has been interested in the parent-professional relationship, family coping with CHARGE, and the challenging behavior in CHARGE. Along with Meg Hefner, Tim edited the articles on behavior for the special issue of the American Journal of Medical Genetics.

Susan HISCUTT, BSBA

Mother of Aaron, a child with CHARGE
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Susan Hiscutt is the Regional Director for Friends of Tennessee Infant Parent Services (TIPS) and volunteers at her son's school and various other organizations that support individuals with disabilities. She is the mother of Aaron who was born with CHARGE Syndrome.

Wendy KEEDY, B.A.

Speech teacher
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Jackie KENLEY

CHARGE Parent of Laura Kenley 22, Family Specialist, California Deaf-Blind Services
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Jackie Kenley received her understanding of CHARGE with the birth of her daughter, Laura, 22 years ago. Jackie has been involved with deaf-blind groups for years and began working for California Deaf-Blind Services in 1996 becoming a Family Specialist in 2000. Jackie is passionate about adult services for people with disabilities and has been a member of the Board of Directors for the ARC of San Francisco for 5 years. Laura will begin her journey beyond school this June and the family is working towards supported living.

Emily KING, B.A.

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I first became involved with CHARGE while working with a child with this syndrome at Kentucky School for the Deaf in 2005-2006. After receiving my degree in Spanish and English from Centre College, I entered the University of Tennessee-Knoxville as a graduate student in the field of Speech and Language Pathology. I soon became involved with the CHARGE research of two professors, Drs. Jim Thelin and Lori Swanson. I received a graduate research assistantship from the University of Tennessee for the summer of 2007 to continue working on language research of children with CHARGE with Drs. Thelin and Swanson.

Cathy KIRSCHER, M.S.

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Cathy Kirscher received her M.S. in Counseling, with a specialization in Rehabilitation Counseling for the Deaf and Hard of Hearing, from Western Oregon University in 1982. She has worked for the past 20 years in the field of dual sensory loss with the Helen Keller National Center (HKNC), as the Regional Representative both in Seattle, Northwest Region, and in San Diego, Southwest Region. She also worked for three years as an Affiliate of HKNC, under a grant at Alliant International University (formerly California School of Professional Psychology), as the coordinator of Research and Training on Mental Health and Deaf-Blindness.

Arno de Kort, MD

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Sarah KRIVENKI

Doctoral Student in Audiology who will be conducting vestibular research at the Conference.

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Dr. Seema R. LALANI

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I'm an Assistant Professor in the Department of Molecular and Human Genetics at Baylor College of Medicine, Houston. My research interests include studying the genetic basis of CHARGE syndrome and understanding the clinical differences between children who have mutations in the CHD7 gene and those who don't.

Robert (Rob) LAST

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Rob is trained as an Early Childhood Teacher with Vision Australia involving children with sensory disabilities in particular in hearing and vision. He has developed communications systems to meet individual needs of children with CHARGE syndrome since the early 1990s and has been an invited presenter at every International CHARGE Syndrome Conference. He is primarily engaged in home based early intervention with families. He has done longitudinal studies of the progress made by people who have CHARGE syndrome, beginning in 1993. This is through video interviews in 1993, 2000 and 2007. Rob has been very active in the Australasian CHARGE association since its inception and help with the even-year Australasian CHARGE conferences.

Kimberly LAUGER, RN

Institutional affiliation: Arizona Deafblind Project

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Kim Lauger is driven to help individuals—and those who care for them—understand the root cause of dysfunction, so attention can be shifted from blame to solution. Kim has one son who struggled with attention and learning difficulties, one son with CHARGE Syndrome, and a daughter for whom learning and “being” is relatively easy. Kim’s professional background includes the fields of pediatric nursing, behavioral science, and deafblindness. She currently has her own practice, ND Solutions, is a provider of HANDLE[®] and a consultant to the Arizona Deafblind Project.

Donna LYNNE, M.Ed.

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Donna is certified as a teacher of the Deaf and Hard of Hearing as well as in the area of Interdisciplinary Early Childhood Education. Donna is also a certified Montessori teacher. She is a graduate of Gallaudet University and is fluent in American Sign Language (ASL). Donna resides in northern Kentucky with four children. In her role on the project she delivers statewide, on-site technical assistance to children birth through fourteen (14) years of age, their families, and their service providers. This includes facilitation and conducting assessments, assisting with the development and implementation of individualized education programs as well as developing individualized communication systems in both home and school settings. As a former classroom teacher and early interventionist, Donna supports educators by modeling teaching strategies and intervention techniques. She assists in providing intensive technical assistance to children with CHARGE, their family and service providers.

Martha M. Majors

Assistant Supervisor Deafblind Program Perkins School for the Blind

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Active and enthusiastic member of the CHARGE Foundation; my daily job responsibilities include the supervision of 12 students with CHARGE; very involved with communication strategies and behavior support for CHARGE children ages 3-18 years.

Betsy L. McGINNITY

Information Specialist

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Betsy L. McGinnity, M.Ed., has been with the DB-LINK project since it began. Ms. McGinnity has a thirty-plus year background in classroom teaching and employment and transition issues for youth who are deafblind. She has administered several federally funded model projects in these areas. She has worked as a technical assistance provider nationally and internationally through the Hilton/Perkins Program. She coordinated the 1997 Hilton/Perkins National Conference on Deafblindness and the Perkins 175th Anniversary History Museum Project. Ms. McGinnity oversees the Samuel P. Hayes Research Library and Archives, the History Museum and the Hilton/Perkins DB-LINK project.

Joe McNULTY

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Joe McNulty has worked in the field of deaf-blindness for thirty years. He has worked as an O&M specialist, a supervisor of residential services and, since 1990, Executive Director of the Helen Keller National Center. He is Co-Chair of the National Coalition on Deaf-Blindness and serves as a special advisor to the National Family Association for Deaf-Blind (NFADB).

Kathy McNULTY

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Kathy McNulty is the Associate Director of the National Consortium on Deaf-Blindness (NCDB) and has worked for more than seventeen years on national deaf-blind technical assistance projects. She has experience in the provision of technical assistance and training, particularly in the areas of transition and parent and family advocacy. Kathy is an advisor to the National Family Association for Deaf-Blind (NFADB) and the CHARGE Syndrome Foundation.

Shirley M. R. MINSTER, M. S. Ed.

Director, Home Education & Family Services / Royal Academy
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Shirley Minster is well known as a friend and advocate of homeschoolers not only in the United States, but internationally. Founder of Home Education & Family Services, a fulltime organization offering a wide variety of resources and helps for homeschooling families, and Royal Academy, a home-based educational K-12 school based on the homeschool mentoring model, Shirley has worked with families for over 25 years. Her consulting work is with individual students, parents, and schools (both public and private). These areas of consultation occur internationally with parents and educators.

She is a Master Degree certified teacher who holds credentials in education, educational guidance, and family counseling. She is an ardent supporter of homeschooling all children no matter what the special need and uses her extensive credentials to advocate for individual families and as an expert witness in court. Shirley's valuable insight into child development and the dynamics of the homeschooling family has helped many parents succeed in their educational choices for their children.

Tina PROCHASKA, MS

Communication Specialist and Sibshop Coordinator
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Tina Prochaska has a BS in Deaf Education and an MS in Curriculum and Instruction. She is Communication Specialist and Sibshop Coordinator at the Tennessee School for the Deaf. Tina has been leading Sibshops since 1992, is a member of the Sibling Support Project's National Advisory Committee and is a member of the Sibling Leadership Network. Tina has a deaf brother.

John W. REIMAN, Ph.D.

Associate Director, National Consortium on Deaf-Blindness
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John Reiman has been involved with deaf/deaf-blind people for 25 years in a variety of contexts including direct service, graduate pre-service training, research and technical assistance/dissemination. He has been the Director of DB-LINK (National Information Clearinghouse on Deaf-Blindness) since 1992. Dr. Reiman has 15 years of family, workplace, special

education, marriage, divorce, and other mediation experience. He specializes in high conflict relationships. John has a Ph.D. in Counseling and is an Advanced Practitioner Member of the Assoc. for Conflict Resolution (ACR). He is a Licensed Professional Counselor (LPC), a Certified (CSC) Sign Language Interpreter (to 2006), and a Clinical Associate with the American Board of Medical Psychotherapists. John has been with the Teaching Research Institute of Western Oregon Univ. for 22 years and works as a Mediation Specialist for the National Center on Dispute Resolution in Special Education. He is a member of the Benton County (OR) and Oregon Dept. of Justice Crisis Response Teams.

Gloria RODRIGUEZ-GIL, M.Ed.

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Gloria Rodriguez-Gil has been a Bilingual English-Spanish Educational Specialist for California Deaf-blind Services (CDBS) for the past eight years. Under this capacity she has provided technical assistance and training to service providers and families of individuals who are deaf-blind from birth to twenty-one, she also has written technical articles for CDBS newsletter. Gloria is also a free-lance consultant for Hilton-Perkins Program in Latin America.

Susan RUZENSKI, M.A.

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Susan Ruzenski received her M. A. in Deaf Education from New York University. She has been working with the deaf-blind community for twenty-six (26) years. She has been the Director-Direct Services at the Helen Keller National Center since 1990. Currently she is a doctoral candidate at Columbia University, Teachers College in the Adult Learning and Leadership Program.

Pamela RYAN, M.A.,

CAGS Licensed Educational Psychologist

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I am a school psychologist in the Deafblind Program at the Perkins School for the Blind in Watertown, MA. I have worked at Perkins for over 30 years and in various capacities at Perkins, but always in the Deafblind Program. My graduate work in School Psychology was done at Gallaudet University. I am a recent appointee to the CHARGE syndrome Board and active on the listserv. I have had the good fortune to meet many of the CHARGE families through my work at Perkins as well as conference participation over the years as well as the listserv.

Dr. Peter C. Scacheri, Ph.D.

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Peter Scacheri graduated with a BS in Biology from Gettysburg College and earned his Ph.D. in Biochemistry and Molecular Genetics from the University of Pittsburgh. His graduate work was focused on the molecular mechanisms underlying inherited forms of muscular dystrophy. His postdoctoral fellowship was in the lab of Francis Collins at the National Human Genome Research Institute at the National Institutes of Health. There he combined mouse genetics and genomics to study a type of cancer that affects the endocrine organs. Peter won several awards during his postdoctoral fellowship, including the NHGRI Intramural Research Award for outstanding scientific achievement. Peter joined the Department of Genetics at Case Western Reserve University in April, 2006. His laboratory, which consists of two graduate students, one postdoctoral fellow, and one technician, is focusing on the role of CHD7 in CHARGE syndrome. Specifically, the Scacheri lab is using cutting-edge genomics to identify genes that are directly regulated by CHD7 during development. Dr. Scacheri's research on CHARGE syndrome is supported by an R01 grant awarded from the National Institute of Child Health and Human Development.

Neal STANGER

Parent of a teenage daughter with CHARGE syndrome

President CHARGE Syndrome Foundation, Inc.

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Neal has been a member of the CHARGE Syndrome Foundation Board for 10 years and is now beginning his 3rd year as president. He is proudest of his contributions to the Foundation that have led to its financial solvency. One fundraising project that he introduced 8 years ago, the Silent Auction at the Conference, has brought in more than \$50,000. He joins the Professional Board this year because he is a presenter in the session on "Training for Fundraisers."

Sheri STANGER, M.A., M.Ed.,

Parent of a teenage daughter with CHARGE syndrome
Immediate Past President of the National Family Association for Deaf-Blind (NFADB)
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Sheri previously worked as a school counselor with children who were blind and deaf-blind. At this conference, she will represent NFADB.

Nancy STEELE

Technical Assistance Specialist, Area 3, National Consortium on Deaf-Blindness
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Nancy Steele has been a Technical Assistance Specialist with the National Consortium on Deaf-Blindness (formerly National Technical Assistance Consortium for Children and Young Adults who are Deaf-Blind (NTAC)) for 5 years. Prior to that Nancy was a Teacher of the Hearing Impaired in Kentucky for 17 years serving students from early intervention through 21. She has been involved with providing technical assistance to state deaf-blind projects in 7 states throughout the southeast in various capacities. She has trained consultants to state deaf-blind projects in the delivery of classroom technical assistance. Nancy has trained many teachers, service providers and families on various topics such as Communication, Instructional Strategies, Person Centered Planning, and Behavior for students who are deaf-blind.

Sharon Stelzer, M.Ed.

Teacher
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Master's degree in education, specializing in Deafblind education. Twenty two years as a classroom teacher working with a variety of children including those with CHARGE. Currently teaching 3 children with CHARGE.

Kathleen STREMEL

National Consortium for Deaf-Blindness (NCDB) Project Director
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Kathleen Stremel has worked in the area of Communication & Language Assessment, Intervention, and Evaluation for students with severe disabilities for the past 30 years. She has written numerous articles and continues to conduct workshops nationally and internationally. Kathleen served as the Project Director in Mississippi for the State Deaf-Blind project and provided direct services to infants, children, and youth with severe disabilities, including children with deaf-blindness. She currently serves as the Director for the National Consortium for Children/Youth Who Are Deaf-Blind. Kat is currently involved in research with children who have CHARGE and Cochlear Implants.

Lori A. SWANSON, Ph.D.

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Dr. Lori A. Swanson is an associate professor at the University of Tennessee. After attending the 2005 CHARGE Conference Dr. Swanson decided to conduct research on communication development in CHARGE. She is a member of the CHARGE Research Group at UT. This group is investigating the language development, hearing, and vestibular function in CHARGE. In addition to presenting their research at the 2007 CHARGE Conference, the group plans to present their findings at the American Speech-Language-Hearing Association Convention in November in Boston. Dr. Swanson is preparing a chapter on communication development for the CHARGE manual. At present she is serving on the Conference Program Advisory Committee and has begun as a member of the Research Committee. Finally, she is honored to serve the Foundation as a Board Member.

Ella L. TAYLOR, Ph.D.

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Ella L. Taylor, Ph.D., is an Associate Research Professor in Teaching Research at Western Oregon University. Currently, she coordinates research and data analysis with the National Consortium on Deaf-Blindness and is the project director for the Outcomes for Children with Cochlear Implants who are Deaf-Blind (an OSEP funded grant focusing on the outcomes of cochlear implants for children/youth with dual sensory impairments). Dr. Taylor's background includes grant management and evaluation, graduate program coordination, university teaching, graduate and undergraduate course

development, and research within special education, teacher education, and the social sciences. She has co-authored book chapters and articles and has presented at numerous national, state and regional conferences. Dr. Taylor received her doctorate in curriculum and instruction from the University of South Florida.

Lori S. Travis, Au.D., CCC-A

Clinical Audiologist at the University of Missouri Health Care ENT/Audiology Clinic

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I recently obtained my Doctor of Audiology degree from the University of Tennessee-Knoxville. I have been practicing as an audiologist at the University of Missouri Audiology Clinic for approximately a year and a half. Through my graduate study at UT, I conducted research in CHARGE Syndrome under the direction of Dr. James Thelin. In particular, I have been investigating how language, motor development, and vestibular function are related in the overall development of a child with CHARGE Syndrome. I also attended that 2005 CHARGE Syndrome conference in Miami, FL.

Conny van RAVENSWAAIJ, MD PhD

Clinical Geneticist

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Between 1979 and 1986 Conny van Ravenswaaij studied medicine at the University of Leiden, Netherlands. After a brief period of pediatric internships a PhD study concerning the surveillance of preterm newborns was started and completed with a thesis in 1993 at the Radboud University Nijmegen. In 1992 she started with her specialization in clinical genetics in Nijmegen and she was registered as a clinical geneticist and clinical cytogeneticist in 1997 and 2002, respectively.

Her main interest has always been children with multiple congenital anomalies and chromosome disorders, including disorders of sexual differentiation. She is also interested in new molecular cytogenetic techniques to find small chromosome aberrations in children with mental retardation and/or congenital anomalies. With the development of the arrayCGH technique in Nijmegen new research possibilities became available and this was the start of many phenotype-genotype studies in chromosome disorders and the discovery of the CHD7 gene involved in CHARGE syndrome.

In September 2006 she changed affiliation to the University Medical Centre Groningen, where she continued her two multi-disciplinary outpatient clinics (for rare chromosome disorders and for CHARGE syndrome) and her studies in these syndromes. She is also involved in a multidisciplinary team for disorders of sexual differentiation and in Pre-implantation Genetic Diagnosis.

Amongst many other activities, she initiated a European project on rare chromosome disorders (www.ECARUCA.net). Beside her work as a clinical (cyto)geneticist she is involved in a number of parent support groups (CHARGE, Wolf-Hirschhorn syndrome, European 11q, Rare chromosome disorders).

For the studies in CHARGE syndrome she collaborates with many other specialties (amongst others ENT and pediatric endocrinology) in Groningen as well as abroad. At this moment the studies focus on clinical variability and phenotype-genotype correlations, puberty development, clinical and embryological overlap with Kallman syndrome, the role of CHD7 in coloboma, and many other aspects of CHARGE syndrome.

Lee Elizabeth WACHTEL, MD

Medical Director, Neurobehavioral Unit, Kennedy Krieger Institute

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Lisa Weir

Mother of Kennedy, her nine year old daughter who has CHARGE syndrome.

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I have been a parent of a child with CHARGE syndrome for nine years. During that time, I have been involved with the formation of a national CHARGE syndrome group in Canada, serving the first term as president. I have also been moderating the CHARGE Syndrome listserv on the Internet for approximately eight years. I have made several presentations about CHARGE, including two at the Dbi World Conference on Deafblindness in 2003, and various others in my region. Currently, I am entering my final year of a concurrent arts and education degree program; upon completion of these degrees, I plan on doing a master's degree in special education, the focus of which will be the education of students with CHARGE syndrome in an inclusive educational setting. I have recently joined the Board of Directors for my first term with the CHARGE Syndrome Foundation, where I will serve as secretary as well as the chair of the Education Committee.

Philip WISMER

Currently a student at Helen Keller National Center

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Philip Wismer is from Doylestown, PA. He recently graduated from Western Pennsylvania School for the Deaf in Pittsburgh, PA. He enjoys reading, watching NASCAR and working on his computer. He is currently a student at Helen Keller National Center in Sands Point, New York. Philip has attended the CHARGE Syndrome conference since 1995.

Kim ZEIGLER

Family Service Coordinator

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Kim resides with her family in Frankfort, Kentucky. She has four children including twin sons who are 16 years of age and have disabilities of varying degrees. One of her sons is on Kentucky's Deaf-Blind Census. She has one daughter and one step-daughter. Kim works directly with families to provide information and support as needed. She maintains on-going contact with all families who have children on the state census. She does this by phone, e-mail and face-to-face contact. Kim makes home visits for all new referrals to the project. She coordinates activities developed to meet the needs of families including training's. She assists in providing intensive technical assistance to children with CHARGE, their family and service providers.