

Home States of Invited Guests

Alabama

Kenneth Hergenrather
 Margaret Hilliard
 Kathy Neno
 Joseph Telfair
 Wladimir Wertelecki

Arizona

Cathy Bischoff
 Molly Dries
 Mari Landreth
 Barbara McGrath
 Dee Quinn
 Vivian OtaWang
 Ruthann Smejkal

Arkansas

Gil Buchanan

California

Tom Bleecker
 George Cunningham
 Betram Lubin
 Ed McCabe
 Elliot Vichinsky

Colorado

Joyce Hooker
 Debra Knapp
 Martha King
 Bill Letson
 Ann McNulty
 Lisa Miller
 Kathy Watters

District of Columbia

Jack Arner
 Scott Becker
 Mary Davidson
 Amy Fine
 Judith Hagopian
 Catherine Hess
 David Lanier
 Deborah Linzer
 Heather Pierce
 Kathleen Rand Reed
 Nachama Wilker

Florida

Jaime Frias
 Garrett Hall
 Patti Hackett
 John Reiss
 Betsy Shenkman
 Syraj Syed
 Donna Wegener

Georgia

Donna Dent
 James Eckman
 Larry Edmunds
 Greg Fay
 Muin Khoury

Hawaii

Sylvia Au

Directory of Invited Guests

Illinois

David Carpenter
 Sunnah Kim
 Tom Tonniges

Indiana

Donna Olsen

Iowa

Jean Anderson
 Jane Borst
 Tonya Diehn
 Greg Fay
 Andrew Penziner

Kansas

Norman Kahn

Louisiana

Jeanne Johnson
 Patricia Sirois

Maryland

Sarah Carr
 Alan Guttmacher
 Kathy Hudson
 Joseph McInerney

Massachusetts

Robin Blatt
 Eric Nisbet-Brown
 Kenneth Bridges
 Anne Comeau
 Linda Conner-Lacke
 Kathleen Barrett-Lewis
 Harvey Levy
 Ann Merrifield

Ellis Neufeld
 Susan Parsons
 Lisa Schalick
 Susan Waisbren
 Deborah Klein Walker
 Nancy Wilber

Michigan

Pat Peyser

Minnesota

Andrew Nelson

Missouri

Vicki Asbury
 Richard Brown
 Aurita Caldwell
 Lori Williamson-Kruse
 Garland Land
 Judith Miles
 Glenda Miller

Nevada

Renee Paper

New Jersey

Frank Desposito

New Mexico

Polly Arango

New York

Katharine Harris
 Donald Mattison
 Kenneth Pass
 Martin Wolfson

North Carolina

Orren Beaty
Anne Manke

Oklahoma

Angela Monson

Ohio

Kathryn Peppe

Pennsylvania

Carlton Dampier
Edwin Naylor
Renee Robinson

Rhode Island

Ellen Amore
Ron Caldarone
John Fulton
Joann Lindenmayer
Hon Fong Louie Mark
Peter Simon
Sharon Terzian

Tennessee

Ellen Clayton
Mary Jane Dewey
H. Lee Fleshood
William Wilson

Texas

Maricela Aguilar
Celia Kaye
Brad Therell

Utah

Jeff Botkin

Vermont

Kay Johnson

Washington

Deb Doyle
Bob Fineman

Wisconsin

Jill Bork Ciske
Christine Cronk
Sharon Fleischfresser
Marsha Malloy
Arvina Thayer

**Federal Government
Representatives**

Tim Baker
Claude Earl Fox
Robert Linkins
Merle McPherson
Marie Mann
Jim Marks
Jane Martin
Paul Nannis
Michele Lloyd-Puryear
Peter Van Dyck

Contact Information for Invited Guests

Meeting One

Translating Recommendations into Action

November 1, 1999

Jean Anderson MA ARNP
State Coordinator
Iowa Dept of Public Health
Lucas Street Office Bldg 5th Floor
321 East 12th St
DeMoines IA 50319
PH 515/281-7584
Fax 515/242-6384
janderso@health.state.ia.us

Jack Arner
Genetic Services Branch
Maternal and Child Health Bureau MCHB
Parklawn Bldg Rm 18A-20
5600 Fishers Ln
Rockville MD 20857
PH 301/443-8900
Fax 301/443-8604
jarnar@hrsa.gov

Polly Arango
Co-founder/Director
Family Voices
1456 Hwy 313
PO Box 769
Algodones NM 87001
PH 505/867-2368
Fax 505/867-6517
parango@familyvoices.org

Sylvia Au
State Genetics Coordinator
Children with Special Health
Care Needs Branch (CSHCN)
Hawaii State Dept Of Health
741 Sunset Ave
Honolulu HI 96816
PH 808/733-9055
Fax 808/733-9068
sau@hgea.org

Timothy Baker
Deputy Director
Office of Genetics & Disease Prevention
4770 Buford Highway MS K-28
Atlanta, GA 30341
PH 770/488-3235
Fax 770/488/3236
tgb2@cdc.gov

Scott Becker
Executive Director
Assoc of Public Health Laboratories
1211 Connecticut Ave NW Suite 608
Washington DC 20036
PH 202/822-5227x201
Fax 202/887-5098
Sbecker@aphl.org

Tom Bleecker PhD
Research Director
World Institute on Disability
510 16th St Suite 100
Oakland CA 94612-1500
PH 510/251-4338
Fax 510/763-4109
tom@wid.org

Jeff Botkin MD
 Professor of Pediatrics and Medical Ethics
 University of Utah
 100 North Medical Dr
 Salt Lake City UT 84113
 PH 801/588-3649
 Fax 801/588-3642
 botkin@howard.genetics.utah.edu

Kenneth Bridges MD
 Director
 Brigham & Women's Hospital
 Division of Hematology
 75 Francis St
 Boston MA 02115
 PH 617/732-5842
 Fax 617/975-0876
 kbridges@rics.bwh.harvard.edu

Gil Buchanan MD
 Medical Director
 Childrens Medical Svcs
 Arkansas Dept of Human Services
 500 South University Ste 200
 Little Rock AR 72205
 PH 501/682-8202
 Fax 501/682-8247
 Gil.Buchanan@medicaid.state.ar.us

David Carpenter PhD
 State Laboratory Director
 Illinois Dept of Public Health
 825 N Rutledge St
 PO Box 19435
 Springfield, IL 62794-9453
 PH 217/782-6562
 Fax 217/524-7924
 dcarpent@idph.state.il.us

Sarah Carr
 Senior Policy Analyst, Executive Secretary
 Secretary's Adv Comm on Genetic Testing
 Office of Recombinant DNA Act
 National Institute of Health
 6000 Executive Blvd Ste 302
 Bethesda MD 20892-7010
 PH 301/435-6753
 Fax 301/496-9839
 sc112@nih.gov

Ellen Clayton MD JD
 Director, Genetics & Hlth Pcly Cntr
 Div of General Pediatrics
 & School of Law
 Vanderbilt University
 Medical Center East 5028
 Nashville TN 37332-8555
 PH 615/936-2425
 Fax 615/936-2419
 ellen.w.clayton@vanderbilt.edu

George Cunningham MD PhD
 Chief, Genetic Disease Branch
 1947 Center Street 3rd Floor
 Berkley CA 94704
 PH 510/540-2552
 Fax 510/849-5102
 gcunning@dhs.ca.gov

Mary Davidson MSW
 Executive Director
 Alliance of Genetic Support Groups
 4301 Connecticut Ave NW Ste 404
 Washington DC 20008-2304
 PH 202/966-5557x207
 Fax 202/966-8553
 mdavidson@geneticsalliance.org

Frank Desposito MD
 Interim Chairman
 UMDMJ-New Jersey Medical School
 Dept of Pediatrics
 185 South Orange Ave RM F-540
 Newark NJ 07103
 PH 973/972-5276
 Fax 973/972-0178
 desposfr@umdmj.edu

Directory of Invited Guests

Amy Fine BSN MPH
Health Policy/ Program Consultant
3372 Stuyvesant Place NW
Washington DC 20015
PH 202/966-6361
Fax 202/966-8439
afinehome@aol.com

Bob Fineman PhD MD
Medical Consultant
Washington State Dept of Health
1511 Third Ave Ste 808
Seattle WA 98101-1632
PH 206/464-6545
Fax 206/389-2812
drbob@u.washington.edu

Jaime Frias MD
Director
University of South Florida
College of Medicine
Birth Defect Center
17 Davis Blvd
Tampa FL 33606
PH 813/233-2623
Fax 813/233-2624
jfrias@med.usf.edu

Alan Guttmacher MD
Sr Advisor to the Director for Clinical
Affairs
National Human Genome Rsrch Institute
9000 Rockville Pike Bldg 31 Rm 4B09
Bethesda MD 20892
PH 301/496-0844
Fax 301/402-0837

Garrett Hall MAMC
Communications Associate
Inst For Child Health Policy
5700 SW 34th St Ste 323
Gainesville FL 32608-5367
PH 352/392-5904 x245
Fax 352/392-8822
grh@ichp.edu

Patti Hackett MEd
Senior Youth Policy Associate
Inst For Child Health Policy
5700 SW 34th St Ste 323
Gainesville FL 32608-5367
PH 352/392-5904 x241
pattihackett@yahoo.com

Judith Hagopian ACSW MPH
Director HRSA Hemophilia Prgrm
Maternal and Child Health Bureau
Genetic Services Branch
5600 Fishers Lane, RM 18A-19
Rockville, MD 20857
PH 301/443-5690
Fax 301/443-8604
jhagopian@hrsa.gov

Kathy Hudson PhD
Director of Policy and Public Affairs
National Human Genome
Research Institute
9000 Rockville Pike Bldg 31 Rm 4B09
Bethesda MD 20892
PH 301/402-0955
Fax 301/402-0837
Kathyh@exchange.nih.gov

Kay Johnson MPH EdM
President
Johnson Group Consulting Inc
175 Red Pine Rd
Hinesburg VT 05461
PH 802/482-3005
Fax 802/482-3008
JohnsonGCI@aol.com
kj813@aol.com

Norman Kahn MD
 VP of Education and Science
 AAFP
 11400 Tomahawk Creek Pkwy
 Leawood KS 66211
 PH 800/274-2237x6500
 Fax 913/906-6092
 nkahn@aafp.org

Celia Kaye MD PhD
 Professor and Chairman
 Dept of Pediatrics
 Univ of TX Hlth Science Ctr
 at San Antonio
 7703 Floyd Curl Drive
 San Antonio TX 78284-7802
 PH 210/567-5202
 Fax 210/567-1758
 kaye@uthscsa.edu

Martha King MPA MSW
 Program Director
 Health Services Program
 Natl Conference of State
 Legislatures (NCSL)
 1560 Broadway Ste 700
 Denver CO 80202-5140
 PH 303/830-2200
 Fax 303/863-8003
 martha.king@ncsl.org

Deborah Klein Walker EdD
 Associate Commissioner
 Bureau of Family and Community Health
 Massachusetts Dept of Public Health
 250 Washington St 5th Fl
 Boston MA 02108-4619
 PH 617/624-6090
 Fax 617/624-6062
 debbie.walker@state.ma.us

Harvey Levy MD
 Senior Associate in Medicine and
 Genetics
 Medicine and Genetics
 Children's Hospital
 300 Longwood Ave
 Boston MA 02115
 PH 617/355-6346
 Fax 617/355-3461
 levyh@a1.tch.harvard.edu

Joann Lindenmayer MPH DVM
 Chronic Disease Epidemiologist
 RI Dept of Health
 3 Capitol Hill
 Providence RI 02908-5097
 PH 401/222-1394x116
 Fax 401/222-4415
 jml@cdc.gov

Robert Linkins PhD
 Center for Disease Control
 Data Management Division
 Systems Development Branch
 1600 Clifton Road NE
 Atlanta, GA 30333
 PH 404/639-8728
 Fax 404/639-8548
 rx13@cdc.gov

Michele Lloyd-Puryear PhD MD
 Branch Chief
 Genetic Services Branch
 Maternal and Child Health Bureau MCHB
 Parklawn Bldg Rm 18A-19
 5600 Fishers Ln
 Rockville MD 20857
 PH 301/443-8998
 Fax 301/443-8604
 Mpuryear@hrsa.gov

Directory of Invited Guests

Deborah Linzer
 Public Health Analyst
 Maternal and Child Health Bureau
 Genetic Services Branch
 5600 Fishers Lane, RM 18A-19
 Rockville, MD 20857
 PH 301/443-9280
 Fax 301/443-8604
 dlinzer@hrsa.gov

Bertram Lubin MD
 Director of Medical Research
 Children's Hospital Oakland Rsrch Inst
 5700 Martin Luther King, JR Way
 Oakland, CA 94609
 PH 510/450-7601
 Fax 510/450-7910
 blubin@chori.org

Marie Mann MD MPH
 Deputy Chief
 Genetic Services Branch, MCHB
 Parklawn Bldg Rm 18A-19
 5600 Fishers Lane
 Rockville MD 20857
 PH 301/443-1080
 Fax 301/443-8604
 MMann@HRSA.gov

Donald Mattison MD
 Medical Director
 March of Dimes
 1275 Mamaroneck Ave
 White Plains NY 10605
 PH 914/997-4649
 Fax 914/428-7849
 Dmattison@modimes.org

Ed McCabe MD PhD
 Professor and Executive Chair
 UCLA Dept. of Pediatrics
 Mattel Children's Hospital at UCLA
 School of Medicine
 10833 LeConte Ave Rm 22-412 MDCC
 Los Angeles CA 90095-1752
 PH 310/825-5095
 Fax 310/206-4584
 Emccabe@mednet.ucla.edu

Joseph McInerney
 Director, Foundation for Genetic
 Education & Counseling
 1615 Thames Street
 Baltimore MD 21231
 PH 410/955-0455
 Fax 410/955-0644
 joemcinerney@genetic-medicine.org

Merle McPherson MD MPH
 Director
 Div Of Svcs For Children With
 Special Health Needs (DSCSHN)
 Maternal & Child Health Bur, HRSA,
 DHHS
 5600 Fishers Ln Rm 18A-27 Parklawn Bldg
 Rockville MD 20857
 PH 301/443-2350
 Fax 301/443-1728
 mmcpherson@hrsa.gov

Ann Merrifield
 President
 Genzyme Genetics
 15 Pleasant Street Connector
 Framingham MA 01701
 PH 508/270-2346
 Fax 508/872-5663
 ann.merrifield@genzyme.com

Paul Nannis
 Director
 Office of Planning
 Evaluation and Legislation HRSA
 5600 Fishers Lane Rm 1433
 Rockville MD 20857
 PH 301/443-2460
 Fax 301/443-9270
 pnannis@hrsa.gov

Edwin Naylor PhD MPH
 President
 Neo Gen Screening, Inc
 110 Roessler Rd
 Pittsburgh PA 15220
 PH 412/341-8658
 Fax 412/341-8926
 ednaylor@neogenscreening.com

Donnal Olsen
 Executive Director
 Indiana Parent Info Ntwrk Inc
 4755 Kingsway Dr Ste 105
 Indianapolis IN 46205
 PH 317/257-8683 x11
 Fax 317/251-7488
 familynetw@aol.com

Vivian OtaWang PhD
 Professor
 College of Education
 Arizona State University
 PO Box 870611
 Tempe AZ 85283
 PH 602/727-6933
 Fax 480/965-0300
 otawang@asu.edu

Renee Paper Rn CCRN
 Program Director
 Hemophilia Foundation of Nevada
 765 Heritage Vista Ave
 Henderson NV 89015
 PH 702/564-4368
 Fax 702/558-2191
 hfnv@earthlink.net

Kathryn Peppe RN MS
 Chief
 Division of Family and Comm Health Svcs
 Ohio Dept of Health
 246 N High ST
 PO Box 118
 Columbus, OH 43266-0118
 PH 614/466-3263
 Fax 614/728-3616
 kpeppe@gw.odh.state.oh.us

Pat Peyser PhD
 Professor of Epidemiology
 Director, Public Health Genetics
 Interdepartmental Concentration
 Univ of MI School of Public Health
 Depart of Epidemiology 109
 Ann Arbor MI 48109
 PH 734/763-4077
 Fax 734/764-3192
 ppeyser@umich.edu

Heather Pierce MPH
 Sr. Analyst, Genetics Policy
 The Association of State & Territorial
 Health Officials (ASTHO)
 1275 K St NW Ste 800
 Washington DC 20005
 PH 202/371-9090x248
 Fax 202/371-9797
 hpierce@astho.org

Dee Quinn MS
 President
 Organization of Teratology Infor Serv
 Univ of Arizona Health Sciences Center
 Dept of OBGYN
 1501 North Campbell
 Tucson AZ 85724
 PH 520/626-4382
 Fax 520/626-5115
 dquinn@u.arizona.edu

Directory of Invited Guests

Kathleen Rand Reed
President
GeoGeneSys
Geographic Genetic Systems
1923 2nd St NW
Washington DC 20001-1667
PH 202/234-8074
Fax 202/234-2506
krreed@bellatlantic.net

John Reiss PhD
Director of Policy & Program Affairs
Inst For Child Health Policy
5700 SW 34th St Ste 323
Gainesville FL 32608-5367
PH 352/392-5904 x224
Fax 352/392-8822
jgr@ichp.edu

Peter Simon MD MPH
Assistant Medical Director
Division of Family Health
Rhode Island Department of Health
3 Capitol Hill
Canon Building Rm 312
Providence RI 02908-5097
PH 401/222-5928
Fax 401/222-1442
peters@doh.state.ri.us

Syraj Syed MAMC
Associate for Technology and Training
Institute For Child Health Policy
5700 SW 34th Street Suite 323
Gainesville FL 32608
PH 352/392-5904x249
Fax 352/392-8822
sys@ichp.edu

Brad Therrell PhD
Director
NNSGRC
1912 W Anderson Ln #210
Austin TX 78757
PH 512/454-6419
Fax 512/454-6509
therrell@uthscsa.edu

Thomas Tonniges MD FAAP
Director
Dept of Community Pediatrics, AAP
141 NW Point Blvd
Elk Grove Village IL 60007-1098
PH 800/433-9016 4723
Fax 847/228-5097
ttonniges@aap.org

Martin Wolfson
Vice President
Neometrics
104 Bellerose Ave
East North Port, NY 11731
PH 800/645-3616
Fax 516/754-1049
mwolfson@neometrics.com

Contact Information for Invited Guests

Meeting Two

Promotion of the Early Identification of Children with Special Health Needs through Infrastructure Development

Maricela Aguilar RN MSN
 Genetics Special Programs Director
 Department: Children's Clinic
 Christus Santa Rosa Health Care
 519 West Houston
 San Antonio TX 78207
 PH 210/704-2866
 Fax 210/704-2651
 marci_aguilar@srhc.lwhs.org

Ellen Amore MS
 Health Policy Analyst
 RI Dept of Health
 3 Capitol Hill Rm 302
 Providence RI 02908-5097
 PH 401/222-4601
 Fax 401/222-1442
 ellena@doh.state.ri.us

Jean Anderson MA ARNP
 State Coordinator
 Iowa Dept of Public Health
 Lucas Street Office Bldg 5th Floor
 321 East 12th St
 DeMoines IA 50319
 PH 515/281-7584
 Fax 515/242-6384
 janderso@health.state.ia.us

Vicki Asbury
 8010 NW Pleasant Ford
 Parkville MO 64152
 PH 816/741-8159
 JDSpicher@aol.com

Sylvia Au
 State Genetics Coordinator
 Children with Special Health
 Care Needs Branch (CSHCN)
 Hawaii State Dept Of Health
 741 Sunset Ave
 Honolulu HI 96816
 PH 808/733-9055
 Fax 808/733-9068
 sau@hgea.org

Timothy Baker
 Deputy Director
 Office of Genetics & Disease Prevention
 4770 Buford Highway MS K-28
 Atlanta GA 30341
 PH 770/488-3235
 Fax 770/488-3236
 tgb2@cdc.gov

Kathleen Barrett-Lewis
 Parent Coordinator
 Family Ties
 584 Randolph Avenue
 Milton, MA 02186
 PH 718/828-7190
 kathleen.lewis@state.ma.us

Cathy Bischoff
 Office of Vital Records
 2727 W Glendale Ave
 Phoenix AZ 85051
 PH 602/255-2501
 Fax 602/255-3259 or 249-3040

Directory of Invited Guests

Robin Blatt JR RN MPH
Genetics Prgm Coordinator/Pub Hlth
Nursing Advisor
MA Genetics Program
Div for Special Health Needs
Bureau of Family & Community Health
MA Dept of Public Health
250 Washington Street 4th FL
Boston MA 02108-4619
PH 617/624-5963
Fax 617/624-5990
robin.blatt@state.ma.us

Jill Bork Ciske
State Genetics Coordinator
WI Division of Public Health
1414 E Washington Ave Rm 167
Madison WI 53703
PH 608/267-7148
Fax 608/267-3824
borkjc@dhfs.state.wi.us

Jane Borst
State Maternal and Child Health Director
IA Dept of Public Health, 5th Floor
321 East 12th Street
Des Moines IA 50319-0075
PH 515/281-4911
Fax 515/242-6384
jborst@health.state.ia.us

Richard Brown PhD FACHE
Bureau Chief
Bureau of Special Health Care Needs
Missouri Department of Health
930 Wildwood St
Jefferson City MO 65109
PH 573/751-6246
Fax 573/751-6237
brownr@mail.health.state.mo.us

Ron Caldarone MSW
Chief, RI Dept. of Health
Ofc of Children w/ Special Hlth Care
Needs
3 Capitol Hill Rm 302
Providence RI 02908-5097
PH 401/222-1185 x112
Fax 401/222-1442
ronc@doh.state.ri.us

Aurita Prince-Caldwell
Bureau Chief
Disability Prevention and Injury Control
Missouri Department Of Health
930 Wildwood
PO Box 570
Jefferson City MO 65102
PH 573/751-6272
Fax 573/526-5348
princa@mail.health.state.mo.us

Anne Comeau PhD
New England Newborn Screening Prgm
Univ of MA Medical School
State Laboratory Institute
305 South Street Rm 610
Jamaica Plain MA 02130
PH 617/983-6321
Fax 617/522-2846
anne.comeau@state.ma.us

Linda Connor-Lacke
95 Caesar Chelor Dr
Wrentham MA 02093-1295
PH 503/384-3745
Fax 503/384-3745
llacke@prodigy.net

Christine Cronk DSC
 Director, Birth Defects Surveillance
 System
 Division of Public Health
 Children with Special Health Care Needs
 1414 E Washington Ave Rm 167
 Madison WI 53703
 PH 608/266-8496
 Fax 608/267-3824
 cronkce@dhfs.state.wi.us

Larry Edmunds
 Chief, State Services Branch
 Div of Birth Defects & Pediatric Genetics
 National Center for Environmental Health
 Center for Disease Control
 4770 Buford Hwy (F45)
 Chamblee GA 30341
 PH 770/488-7160
 Fax 770/488-7197
 Ide2@cdc.gov

Tonya Diehn MS
 Grant Coordinator
 Dept of Community Health/Family
 and Community Health Division
 Lucas Street Office Building
 321 East 12th St
 Des Moines IA 50319
 PH 515/281-7584
 Fax 515/242-6384
 tdiehn@health.state.ia.us

Greg Fay
 Information Systems Director
 IA Dept of Public Health
 321 East 12th Street
 Des Moines IA 50319-0075
 PH 515/281-6601
 Fax 515/281-4958
 gfay@idhp.state.ia.us

Deb Doyle MS CGC
 State Coordinator for Genetics Services
 Washington State Dept of Health
 Community and Family Health
 Genetic Services Section
 1511 Third Ave Ste 808
 Seattle WA 98101
 PH 206/464-7752
 Fax 206/389-2812
 DLD2303@DOH.WA.GOV

Bob Fineman PhD MD
 Medical Consultant
 Washington State Dept of Health
 1511 Third Ave Ste 808
 Seattle WA 98101-1632
 PH 206/464-6545
 Fax 206/389-2812
 drbob@u.washington.edu

Molly Dries MS
 Executive Director, AZEIP
 1717 W Jefferson
 Phoenix AZ 85007
 PH 602/542-5463
 Fax 602/542-5552

Sharon Fleischfresser MD MPH
 CSHCN Medical Director
 Wisconsin Program for
 Children w/ Special Health Care Needs
 1414 E Washington Ave Rm 199
 Madison WI 53703-3043
 PH 608/266-3674
 Fax 608/267-3824
 fleissa@dhfs.state.wi.us

Directory of Invited Guests

John Fulton PhD
State Chronic Disease Director
RI Dept of Health
3 Capitol Hill Rm 403
Providence RI 02908-5097
PH 401/222-1394x115
Fax 401/861-5751
fult100w@aol.com

Patti Hackett MEd
Associate for Youth Policy
Inst For Child Health Policy
5700 SW 34th St Ste 323
Gainesville FL 32608-5367
PH 888/433-1851 or 352/392-5904 x241
Fax 352/392-8822
ph8@ichp.edu
pattihackett@yahoo.com

Garrett Hall MAMC
Communications Associate
Inst For Child Health Policy
5700 SW 34th St Ste 323
Gainesville FL 32608-5367
PH 352/392-5904 x245
Fax 352/392-8822
grh@ichp.edu

Catherine Hess MSW
Executive Director
Association of Maternal and Child
Health Programs (AMCHP)
1220 19th St NW Ste 801
Washington DC 20036
PH 202/775-0436
Fax 202/775-0061
chess@amchp.org

Joyce Hooker
CO State Genetics Coordinator
CO Dept of Health and Environment
FCHSD-MAS-A4
4300 Cherry Creek Dr South
Denver CO 80246-1530
PH 303/692-2423
Fax 303/782-5576
joyce.hooker@state.co.us

Kay Johnson MPH EdM
President
Johnson Group Consulting Inc
175 Red Pine Rd
Hinesburg VT 05461
PH 802/482-3005
Fax 802/482-3008
JohnsonGCI@aol.com
kj813@aol.com

Sunnah Kim RN MS
Manager, Screening Programs
American Academy of Pediatrics
141 Northwest Point Blvd
Elk Grove Village IL 60007-1098
PH 847/852-4924
Fax 847/228-6432
skim@aap.org

Martha King MPA MSW
Program Director
Health Services Program
Natl Conference of State
Legislatures (NCSL)
1560 Broadway Ste 700
Denver CO 80202-5140
PH 303/830-2200
Fax 303/863-8003
martha.king@ncsl.org

Debra Knapp JD
 Knapp & Sachs Law Firm
 2264 Dexter Street
 Denver CO 80207
 PH 303/892-3755
 Fax 303/892-3882
 knappsachs@aol.com

Garland Land
 Missouri Dept of Health
 920 Wildwood Box 570
 Jefferson City MO 65102
 PH 573/751-6272
 Fax 573/526-4102
 landg@mail.health.state.mo.us

Mari Landreth
 13030 N 77th Ave
 Pecria AZ 85381
 PH 623/979-1787
 marilandreth@hotmail.com

Bill Letson
 Director
 CO Dept of Health and Environment
 DCHSD-MGS-A4
 4300 Cherry Creek Dr South
 Denver CO 80246
 PH 303/692-2424
 Fax 303/782-5576
 bill.letson@state.co.us

Joann Lindenmayer DVM
 RI Dept of Health
 3 Capitol Hill Rm 408
 Providence RI 02908-5097
 PH 401/222-1394x116
 Fax 401/861-5751

Robert Linkins PhD
 Center for Disease Control
 Data Management Division
 Systems Development Branch
 1600 Clifton Rd NE
 Atlanta GA 30333
 PH 404/639-8728
 Fax 404/639-8548
 Rx13@cdc.gov

Michele Lloyd-Puryear PhD MD
 Branch Chief
 Genetic Services Branch
 Maternal and Child Health Bureau MCHB
 Parklawn Bldg Rm 18A-19
 5600 Fishers Ln
 Rockville MD 20857
 PH 301/443-8998
 Fax 301/443-8604
 Mpuryear@hrsa.gov

Marsha Malloy RN BSN MBA
 Research Nurse
 Medical College of Wisconsin
 Dept. of Pediatrics-Neonatology
 8701 Watertown Plank Rd
 Milwaukee WI 53226
 PH 414/456-4327
 Fax 414/456-6651
 mmalloy@mcw.edu

Marie Mann MD MPH
 Deputy Chief
 Genetic Services Branch, MCHB
 Parklawn Bldg Rm 18A-19
 5600 Fishers Lane
 Rockville MD 20857
 PH 301/443-1080
 Fax 301/443-8604
 MMann@HRSA.gov

Directory of Invited Guests

Hon Fong Louie Mark PhD FACMG
2 Pine Top Road
Harrington RI 02806
PH 401/246-0487
Fax 401/246-0487
HonFong_Mark@Brown.edu

Barbara McGrath
Program Project Specialist
Office of Vital Records
AZ Dept of Health Services
2727 W Glendale Ave
Phoenix, AZ 85051
PH 602/255-2501
Fax 602/255-3259
bmcgrat@hs.state.az.us

Ann McNulty
Manager
FCHD Data Services
FCHSD-A4-Dat
4300 Cherry Creek Dr South
Denver CO 80246-1530
PH 303/692-2311
Fax 303/782-5576 (call 1st)
ann.mcnulty@state.co.us

Merle McPherson MD MPH
Director
Div of Svcs for Children with
Special Health Needs (DSCSHN)
Maternal & Child Health Bur HRSA
DHHS
5600 Fishers Ln Rm 18A-27 Parklawn
Bldg
Rockville MD 20857
PH 301/443-2350
Fax 301/443-1728
mmcpherson@hrsa.gov

Glenda Miller MPH BSN
Director
Div of Maternal Child & Family Health
Missouri Dept of Health
930 Wildwood
Jefferson City MO 65109/
PH 573/751-6252
Fax 573/526-5348
milleg@mail.health.state.mo.us

Lisa Miller MD MSPH
Director
Colo Dept of Public Health &
Environment
4300 Cherry Creek Dr South
Denver CO 80246-1530
PH 303/692-2663
Fax 303/782-0904
usa.miller@state.co.us

Andrew Penziner MD MS
Program Associate
State Children w/ Special Hlth Care
Needs
University Hospital School
100 Hawkins Dr Rm 254
Iowa City IA 52242-1011
PH 319/356-1456
Fax 319/356-3715
andrew-penziner@uiowa.edu

Heather Pierce MPH
Sr. Analyst, Genetics Policy
The Association of State & Territorial
Health Officials (ASTHO)
1275 K St NW Ste 800
Washington DC 20005
PH 202/371-9090x248
Fax 202/371-9797
hpierce@astho.org

John Reiss PhD
 Director, Policy & Program Affairs
 Inst For Child Health Policy
 5700 SW 34th St Ste 323
 Gainesville FL 32608-5367
 PH 888/433-1851 or 352/392-5904 x224
 Fax 352/392-8822
 jgr@ichp.edu

Lisa Schalick
 Center Director
 MA Center for Birth Defects
 Research Prevention
 250 Washington St 5th Fl
 Boston MA 02108-4619
 PH 617/624-5507
 Fax 617/624-5574
 lisa.schalick@state.ma.us

Peter Simon MD MPH
 Assistant Medical Director
 Division of Family Health
 Rhode Island Department of Health
 3 Capitol Hill
 Canon Building Rm 312
 Providence RI 02908-5097
 PH 401/222-5928
 Fax 401/222-1442
 peters@doh.state.ri.us

Ruthann Smejkal PhD
 Director
 Newborn Screening Program
 411 N 24th St
 Phoenix AZ 85008
 PH 602/220-6487
 Fax 602/220-6488
 rsmejka@hs.state.az.us

Syraj Syed MAMC
 Associate for Technology and Training
 Institute for Child Health Policy
 5700 SW 34th Street Suite 323
 Gainesville FL 32608
 PH 352/392-5904x249
 Fax 352/392-8822
 sys@ichp.edu

Sharon Terzian
 Family Expert Leader
 RI Dept of Health
 3 Capitol Hill Rm 302
 Providence RI 02908-5097
 PH 401/222-5372
 Fax 401/222-1442
 flamingo@ids.net

Arvina Thayer
 Family Expert Leader
 4901 Waukesha St
 Madison WI 53705
 PH 608/238-6928

Brad Therrell PhD
 Director
 NNSGRC
 1912 W Anderson Ln #210
 Austin TX 78757
 PH 512/454-6419
 Fax 512/454-6509
 therrell@uthscsa.edu

Thomas Tonniges MD FAAP
 Director
 Dept of Community Pediatrics
 141 NW Point Blvd
 Elk Grove Village IL 60007-1098
 PH 800/433-9016 4723
 Fax 847/228-5097
 ttonniges@aap.org

Directory of Invited Guests

Kathy Watters
Director, Community Consultation Team
Health Care Program for Children
with Special Needs
4300 Cherry Creek Dr South
Denver CO 80222-1530
PH 303/692-2418
Fax 303/782-5576
kathy.watters@state.co.us

Nancy Wilber
MA Genetics Program
Div for Special Health Needs
Bureau of Family & Community Health
250 Washington St 4th Fl
Boston MA 02108-4619
PH 617/624-5963
Fax 617/624-6062

Martin Wolfson
Vice President
Neometrics
104 Bellerose Ave
East North Port, NY 11731
PH 800/645-3616
Fax 516/754-1049
mwolfson@neometrics.com

Contact Information for Invited Guests

Meeting Three

Improvement and integration of Health Services for Infants and Children with Genetic Condition

Orren Beaty, III PhD DO
 Pediatric Hematologist/ Oncologist
 Mission St Joseph's Health System
 509 Biltmore Ave
 Asheville NC 28801
 PH 828/254-4701
 Fax 828/254-3692
 msj.hdroxb@memo.msj.org

Carlton Dampier MD
 Associate Professor
 Department fo Pediatrics
 St Christopher's Hospital
 Erie Avenue at Front Street
 Philadelphia PA 19134
 PH 215/427-5361
 Fax 215/427-6684
 carlton.dampier@drexel.edu

Donna Dent
 Senior Research Coordinator
 Emory School of Medicine
 69 Butler Street, SE
 Atlanta GA 30303
 PH 404/616-3262
 Fax 404/577-9107
 dzdent@emory.edu

James Eckman MD
 Director
 Georgia Comprehensive Sickle Cell Center
 Emory School of Medicine Dept. of
 Medicine
 69 Butler Street SE
 Atlanta GA 30303
 PH 404/616-5982
 Fax 404/577-9107
 jeckmann@emory.edu

H. Lee Fleshood PhD MPA
 Director
 Genetic & Newborn Screening Program
 Maternal and Child Health
 425 5th Ave North 5th Floor
 Nashville Tn 37247-4701
 PH 615/741-1471
 Fax 615/741-1063
 lfleshood@mail.state.tn.us

Ms Holly Grason MA
 Faculty Associate
 Natl Policy Ctr for Children with
 Special Health Care Needs
 Johns Hopkins School of Public Hlth
 624 N Broadway Rm 257
 Baltimore MD 21205
 PH 410/502-5443
 Fax 410/955-2303
 hgrason@jhsph.edu

Garrett Hall MAMC
 Communications Associate
 Inst For Child Health Policy
 5700 SW 34th St Ste 323
 Gainesville FL 32608-5367
 PH 352/392-5904 x245
 Fax 352/392-8822
 grh@ichp.edu

Katharine Harris
 Wadsworth Center, E-299
 Po Box 509
 Albany NY 12201-0509
 PH 518/484-7148
 Fax 518/473-1733
 kbh02@health.state.ny.us

Directory of Invited Guests

Kenneth Hergenrather MSED MRC CRC
Genetics Program Evaluator
Children's Rehabilitative Services
2129 E South Blvd
PO Box 11586
Montgomery, AL 36111-0586
PH 334/844-5943
Fax 334/844-2080
khergen@aol.com

Margaret Hilliard BSN
Pregnancy Outcome Registrar
Dept of Med Genetics
CCCB 214/ 307 University Blvd
Mobile AL 36688
PH 334/460-7500
Fax 334/460-7684
philliard@usmail.usouthal.edu

Kay Johnson MPH EdM
President
Johnson Group Consulting Inc
175 Red Pine Rd
Hinesburg VT 05461
PH 802/482-3005
Fax 802/482-3008
JohnsonGCI@aol.com
kj813@aol.com

Jeanne Johnson MPH
Assistant Director, Sickle Cell Center
Tulane Medical School
1440 Canal St Ste 1604
New Orleans LA 70112
PH 504/584-3596
Fax 504/585-6013
jjohnson@tmspop.tmc.tulane.edu

Harvey Levy MD
Senior Associate in Medicine & Genetics
Medicine and Genetics
Children's Hospital
300 Longwood Ave
Boston MA 02115
PH 617/355-6346
Fax 617/355-3461
levyh@a1.tch.harvard.edu

Michele Lloyd-Puryear PhD MD
Branch Chief
Genetic Services Branch
Maternal and Child Health Bureau MCHB
Parklawn Bldg Rm 18A-19
5600 Fishers Ln
Rockville MD 20857
PH 301/443-8998
Fax 301/443-8604
Mpuryear@hrsa.gov

Anne Manke RN
Supervisor, Pediatric Outpatient Unit
Mission St. Joseph's Health System
509 Biltmore Ave
Asheville NC 28801
PH 828/254-4701
Fax 828/254-3692

Marie Mann MD MPH
Deputy Chief
Genetic Services Branch, MCHB
Parklawn Bldg Rm 18A-19
5600 Fishers Lane
Rockville MD 20857
PH 301/443-1080
Fax 301/443-8604
MMann@HRSA.gov

Jane Martin
Sr Public Health Advisor
5600 Fishers Lane, Rm 11-25
Rockville, MD 20857
PH 301/443-7070
Fax 301/443-2173
jmartin@hrsa.gov

Merle McPherson MD MPH
 Director
 Div of Svcs for Children with
 Special Health Needs (DSCSHN)
 Maternal & Child Health Bur HRSA
 DHHS
 5600 Fishers Ln Rm 18A-27 Parklawn
 Bldg
 Rockville MD 20857
 PH 301/443-2350
 Fax 301/443-1728
 mmcpherson@hrsa.gov

Judith Miles MD PhD
 Director
 Division of Medical Genetics
 Professor of Child Health
 University of Missouri Hospital & Clinics
 1 Hospital Drive
 Columbia MO 65212
 PH 573/882-6991
 Fax 573/884-3543
 Milesjh@health.missouri.edu

Andrew Nelson PhD
 Executive Director
 Health Partners Research Foundation
 8100 34th Ave South
 7th floor
 Minneapolis MN 55440-1524
 PH 612/883-5014
 Fax 612/883-5022
 andrew.f.nelson@healthpartners.com

Kathy Neno
 Birth Defects Surveillance Nurse/Project
 Coordinator
 Dept of Medical Genetics
 CCCB 214/ 307 University Blvd.
 Mobile AL 36688
 PH 334/460-7500
 Fax 334/460-7684
 kneno@usmail.usouthal.edu

Ellis Neufeld MD PhD
 Director Clinical Hematology
 Children's Hospital Boston
 300 Longwood Ave Enders 720
 Boston MA 02115
 PH 617/355-8183
 Fax 617/734-6791
 neufeld@al.tch.harvard.edu

Eric Nisbet-Brown MD PhD
 Director Thalassemia Program
 Children's Hospital Boston
 300 Longwood Ave, DFCI, Enders 720
 Attn: Kristin Collins
 Boston MA 02115
 PH 617/632-3597
 Fax 617/632-5757
 eric_nisbet-brown@dfci.harvard.edu

Susan Parsons MD MRP
 Hematology/Oncology, DFCI
 Dana Farber Cancer Institute
 Children's Hospital Boston, Enders 720
 300 Longwood Ave
 Attn: Kristin Collins
 Boston MA 02115
 PH 617/632-4932
 Fax 617/632-2095
 susan_parsons@dfci.harvard.edu

Kenneth Pass PhD
 Chief Lab of Newborn Screening &
 Genetic Services
 Newborn Screening Program
 Wadsworth Center
 NYS Dept of Health
 Po Box 509, Loading Dock J
 Albany NY 12201-0509
 PH 518/473-1993
 Fax 518/486-2095
 kpass@wadsworth.org

Directory of Invited Guests

Renee Robinson PhD
Research Psychologist
St. Christopher's Hospital for Children
Div of Hematology/Oncology
Front Street at Erie Ave
Philadelphia PA 19134-1095
PH 215/427-4615
Fax 215/427-4281
m.renee.robinson@drexel.edu

Elizabeth Shenkman PhD
Institute For Child Health Policy
5700 SW 34th St Ste 323
Gainesville FL 32608-5367
PH 352/392-5904 x222
Fax 352/392-8822
eas@ichp.edu

Patricia Sirois PhD
Developmental Psychologist
Tulane University Medical Center
1440 Canal Street Suite 1604
New Orleans LA 70112
PH 504/585-6011
Fax 504/585-6014
psirois@tmcpop.tmc.tulane.edu

Syraj Syed MAMC
Associate for Technology and Training
Institute For Child Health Policy
5700 SW 34th Street Suite 323
Gainesville FL 32608
PH 352/392-5904x249
Fax 352/392-8822
sys@ichp.edu

Joseph Telfair DrPH MSW MPH
Assistant Professor
Dept of Maternal & Child Health
School of Public Health
Univ of Alabama @ Birmingham
1665 University Blvd Ste 320
Birmingham AL 35294-0022
PH 205/934-1371
Fax 205/934-8248
jtelfair@uab.edu

Brad Therrell PhD
Director
NNSGRC
1912 W Anderson Ln #210
Austin TX 78757
PH 512/454-6419
Fax 512/454-6509
therrell@uthscsa.edu

Susan Waisbren PhD
Associate Professor Psychology
Children's Hospital, IC Smith
300 Longwood Ave
Boston MA 02115
PH 617/355-4685
Fax 617/355-3461
waisbren@al.tch.harvard.edu

Donna Wegener MA
Research Coordinator
Institute For Child Health Policy
5700 SW 34th St Ste 323
Gainesville FL 32608-5367
PH 352/392-5904x
Fax 352/392-8822
dhw@ichp.edu

Wladimir Wertelecki MD
Dept. of Medical Genetics
University of South Alabama
307 University Blvd, Rm 214 CCCB
Mobile AL 36688-0002
PH 334/460-7505
Fax 334/460-7684
wwertele@usamail.usouthal.edu

Nachama Wilker
Associate Director
Alliance of Genetic Support Groups
4301 Connecticut Ave
Washington DC 20008-2304
PH 202/966-5557x204
Fax 202/966-8553
nwilker@geneticalliance.org

Lori Williamson-Kruse MS CGC
Genetics Counselor
Coordinator of Southern Missouri
Regional Genetic Services
100 West Hwy 60, Suite 1
Mtn. View MO 65548
PH 417/934-5605
Fax 417/934-1704
williamson-krusel@missouri.edu

William Wilson
Coordinator of Clinical Services
University of TN Memphis
Boling Center for Development
Disabilities
711 Jefferson Avenue
Memphis TN 38105
PH 901/448-6575
Fax 901/448-7097
wwilson@utmem.edu