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ABSTRACT

The purpose of this directory is to facilitate networking and collaboration among those caring for or providing support services to children with chronic illness or disabling conditions. It is hoped that this directory will enable parents to identify other parents who share their interests and concerns, as well as assist professionals in locating parents whose skills and expertise can assist them in improving community support for children with special needs and their families. The directory, which includes a section for Canada, is organized by state and province under which parents are listed alphabetically. Information provided for each parent includes name, address, telephone numbers, child's or children's disability, group affiliation, health care facility where child receives majority of care, the parent's skills and interests, the parent's experiences in promoting a family-centered approach to health care, the parent's profession, and the year(s) during which the parent has participated in the association's Parent Network meetings. Indexes are provided for parents' names and for disabilities. (VW)

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# Parent Resource Directory

for  
Parents and Professionals  
Caring for Children with  
Chronic Illness or Disabilities

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1st Edition  
February 1987



Association for the Care of Children's Health

EC 201209

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# Parent Resource Directory

1st Edition  
February 1987



**Association for the Care of Children's Health**  
3615 Wisconsin Avenue, N.W., Washington, D.C. 20016  
(202)244-1801 or (202) 244-8922

## Introduction

The purpose of this directory is to facilitate networking and collaboration among those caring for or providing support services to children with chronic illness or disabling conditions. It is hoped that this directory will enable parents to identify other parents who share their interests and concerns, as well as assist professionals in locating parents whose skills and expertise can assist them in improving community support for children with special needs and their families.

This is the first edition of the Parent Resource Directory. An expanded and updated edition will be published in the summer of 1987. A Parent Resource Directory Information Form can be found on page 85 of this directory. Please share this form with parents who would like to be included in the future editions of the directory, or to make corrections or changes in listings in this edition. Completed forms should be returned to ACCH by June 15, 1987. In addition, please use the evaluation form on page 89 to give us feedback on ways to improve this directory and increase its usefulness.

We hope that this directory will be a valuable resource to those who are caring for children with special needs. We look forward to hearing from you and welcome your suggestions.

## Organization of the Directory

The directory is organized by state and province, with parents listed alphabetically within each state or province. In addition, there is a general alphabetical index of parents, as well as an index listing parents by their child's disability at the end of the directory. The following information is presented in this directory:

**Parent Name**

Address

Phone (when two numbers are given the first one is the daytime phone)

Child's or children's disability

Group affiliation

Health care facility where child receives majority of care

The parent's skills and interests

The parent's experiences in promoting a family-centered approach to health care

Parent's profession

Year(s) that parent has participated in ACCH Parent Network meetings

When categories of information are not applicable or were not provided by the parent, they are omitted. An asterisk (\*) before a group affiliation indicates that it is a Parent Training and Information Center, a federally funded program to provide information to parents on the special education laws.

## **ARIZONA**

**Barbara Hopkins**  
1005 E. Carver Road  
Tempe, AZ 85284  
602 838-9006

**Child's disability:** Prune Belly Syndrome; scoliosis  
**Group affiliations:** Prune Belly Syndrome Parent Network  
Arizona Consortium for Children with Chronic  
Illness - Director

**Skills and interests:** Parent-to-parent support and advocacy;  
parent/professional collaboration  
**Experience:** Parent Representative, Arizona Consortium for Children  
with Chronic Illness; public speaking; leading training for health  
providers/teachers; promoting legislation; starting or maintaining  
support groups; working with state health departments

**Profession:** R.N.

**Participation in ACCH Parent Network meetings (years):** 1986

**Susan Larkin**  
720 E. Brentrup  
Tempe, AZ 85283  
602 897-9745

**Child's disability:** Congenital heart defect  
**Group affiliation:** Arizona Consortium for Children with Chronic  
Illness

**Health care facility where child receives majority of care:** Phoenix  
Children's Hospital - Phoenix, AZ

**Skills and interests:** Parent/professional collaboration  
**Experience:** Chairperson, Parent Advisory Council, Phoenix Children's  
Hospital; public speaking; leading training for health  
providers/teachers; promoting legislation; working with state health  
departments

**Profession:** Executive Director, Arizona Consortium for Children with  
Chronic Illness

**Susan Mann**  
2005 N. Central  
Suite 100  
Phoenix, AZ 85004  
602 271-4012  
602 969-8209

**Child's disability:** Multiple handicaps; medically fragile (deceased)  
**Group affiliation:** \*Pilot Parents - Program Coordinator  
**Skills and interests:** Parent-to-parent support; bereavement issues; working with families of medically fragile and at-risk children  
**Experience:** Public speaking; leading training for health providers/teachers; promoting legislation; starting or maintaining support groups; working with state health departments  
**Profession:** Program Coordinator, \*Pilot Parents

**Betsy Trombino**  
2005 N. Central, #100  
Phoenix, AZ 85004  
602 271-4012  
602 942-8626

**Child's disability:** Dwarfism; orthopedic complications  
**Group affiliation:** \*Pilot Parents - Program Director  
**Skills and interests:** Parent-to-parent support; statewide issues for medically at-risk individuals; services for medically fragile  
**Experience:** Member, Arizona Consortium for Children with Chronic Illness; Advisory Board Member, NICHCY (National Information Center for Handicapped Children and Youth); Member, Parent Advisory Council, Phoenix Children's Hospital; public speaking; leading training for health providers/teachers; promoting legislation; starting or maintaining support groups; working with state health departments  
**Profession:** Program Director, \*Pilot Parents  
**Participation in ACCH Parent Network meetings (years):** 1984, 1986

## **ARKANSAS**

**Susan Gregory**  
Route 3 Box 350 G  
Rogers, AR 72756  
501 636-2410  
501 631-6202

**Child's disability:** Seizures controlled by brain surgery  
**Skills and interests:** Parent to parent support; working with families with children having brain surgery  
**Profession:** Teacher

**CALIFORNIA**

**Donna G. Albrecht**  
4603 Lincoln Drive  
Concord, CA 94521  
415 825-6861

**Child's disability:** Werdnig-Hoffmann disease  
**Group affiliations:** Werdnig-Hoffmann Parent Support Group  
Muscular Dystrophy Association  
Families of Spinal Muscular Atrophy  
**Health care facility where child receives majority of care:** Kaiser -  
San Francisco, CA  
**Skills and interests:** Parent-to-parent support; sports programs for  
children with disabilities  
**Experience:** Public speaking; leading training for health  
providers/teachers; starting or maintaining support groups  
**Profession:** Freelance writer  
**Participation in ACCH Parent Network meetings (years):** 1986

**Jane Armfield**  
544 87th Street  
Colma, CA 94015  
415 992-7095

**Child's disability:** Ondine's curse  
**Health care facility where child receives majority of care:** Children's  
Hospital - San Francisco, CA  
**Skills and interests:** State funding for home care for medically  
fragile  
**Experience:** Leading training for health providers/teachers  
**Participation in ACCH Parent Network meetings (years):** 1986

**Sherelyn Campbell**  
1015 Cedar Street  
Santa Cruz, CA 95060  
408 335-7404

**Children's disabilities:** Portal hypertension; hematological conditions  
Atonic bladder/stoma

**Group affiliation:** Circle of Hope - Founder

**Health care facilities where children receive majority of care:**

Stanford University Medical Center - Stanford, CA; Children's Hospital  
at Stanford - Palo Alto, CA

**Skills and interests:** Parent-to-parent support; editor of monthly  
newsletter; bereavement issues

**Experience:** Member, Parent Advisory Board, Children's Hospital at  
Stanford; public speaking; leading training for health  
providers/teachers; starting or maintaining support groups; working  
with state health departments

**Participation in ACCH Parent Network meetings (years):** 1986

**June Carrin**  
2378 Sutter Street  
San Francisco, CA 94115  
415 346-6998  
415 728-7071

**Children's disabilities:** Nager's Syndrome  
Severely deaf

**Skills and interests:** Support for families; adoption of children with  
handicaps; public awareness of children with special needs

**Experience:** Public speaking; leading training for health  
providers/teachers; promoting legislation; starting or maintaining  
support groups; working with state health departments

**Profession:** Clinical psychologist

**Participation in ACCH Parent Network meetings (years):** 1936

**Joan Cassel**  
2741 Valley Street  
San Francisco, CA 94123  
415 346-6858  
415 567-4014

**Child's disability:** Down Syndrome

**Group affiliation:** Support for Parents With Special Children -  
Education Director

**Health care facility where child receives majority of care:** Children's  
Hospital - San Francisco, CA

**Skills and interests:** Parent-to-parent support and discussion groups;  
information and resources for parents; networking with parents of  
children with similar needs

**Experience:** Public speaking; leading training for health providers/  
teachers; starting or maintaining support groups; working with state  
health departments

**Profession:** Social worker; doctoral student in educational psychology

**Kerry Dunn**  
972 Adams Street  
Albany, CA 94706-2022  
415 526-9351

**Child's disability:** Cystic fibrosis

**Health care facility where child receives majority of care:** Children's  
Hospital - Oakland, CA

**Skills and interests:** Insurance coverage for high risk groups; parent-  
to-parent support; parent involvement in policy development

**Experience:** Former Director, Kentucky Cystic Fibrosis Services;  
starting or maintaining support groups; working with state health  
departments

**Participation in ACCH Parent Network meetings (years):** 1986

**Mary Fauvre**  
8833 Woodley Avenue  
Sepulveda, CA 91343  
213 825-8529  
818 892-7915

**Child's disability:** Leukemia (ALL)

**Health care facility where child receives majority of care:** UCLA  
Hospital - Los Angeles, CA

**Skills and interests:** Support to parents of chronically ill children

**Experience:** Public speaking; leading training for health  
providers/teachers; starting or maintaining support groups; working  
with state health departments

**Profession:** Parent Liaison, Oncology Unit - UCLA Hospital

**Participation in ACCH Parent Network meetings (years):** 1985, 1986

**Betty Finkle**  
16000 West Road  
Los Gatos, CA 95030  
408 354-4188

**Child's disability:** Hemophilia (classical)  
**Group affiliation:** Northern California Hemophilia Foundation -  
Membership Chairperson  
**Health care facility where child receives majority of care:** Stanford  
Children's Hospital - Palo Alto, CA  
**Skills and interests:** Parent-to-parent support; hospice care  
**Experience:** Starting or maintaining support groups  
**Profession:** R.N.; Volunteer, Hospice of the Valley

**Sharon Gilbert**  
131 Miramonte  
Fullerton, CA 92635  
714 871-2864

**Child's disability:** Sturge-Weber Syndrome  
**Skills and interests:** Training medical and educational professionals;  
teaching parenting classes; parent advocacy; parent/professional  
collaboration  
**Experience:** Developed curriculum for nurses caring for children with  
handicaps; public speaking; leading training for health  
providers/teachers; promoting legislation; starting or maintaining  
support groups; working with state health departments  
**Profession:** Consultant/Counselor; freelance lecturer on children's  
health care issues  
**Participation in ACCH Parent Network meetings (years):** 1985, 1986

**Sharman Davis Jamison**  
1033 North La Jolla  
Los Angeles, CA 90046  
213 663-3223  
213 650-4877

**Child's disability:** Autism; profoundly deaf  
**Group affiliation:** Lanterman Regional Center  
**Health care facility where child receives majority of care:** Children's  
Hospital - Los Angeles, CA  
**Skills and interests:** Sales and marketing of educational music  
programs for children aged 3 to 9  
**Experience:** Member and past President, Board of Directors, Lanterman  
Regional Center; public speaking; promoting legislation  
**Profession:** National Sales Director, Educational Music for Children

**Monica Loose Jones**

433 E. Pedregosa Street  
Santa Barbara, CA 93103  
805 569-2407

**Child's disability:** Werdnig-Hoffmann disease  
**Group affiliations:** Families of Spinal Muscular Atrophy  
SKIP  
Leukodystrophy Group

**Skills and interests:** All aspects of pediatric home care; comfort care for the terminally ill

**Experience:** Member, state and national task forces on home care of medically fragile children; public speaking; leading training for health providers/teachers; promoting legislation; working with state health departments

**Profession:** Author, Home Care for the Chronically Ill or Disabled

**Child:** A Manual & Sourcebook for Parents and Professionals; consultant on issues related to pediatric home care

**Participation in ACCH Parent Network meetings (years):** 1984, 1985.

**Anna Belle Kaufman**

1784 N. Crescent Heights Blvd.  
Los Angeles, CA 90069  
213 656-6193

**Child's disability:** Bronchopulmonary dysplasia; tracheotomy and gastrostomy now closed; immune deficiency

**Group affiliation:** Good Beginnings

**Health care facility where child receives majority of care:**

Cedars-Sinai Medical Center - Los Angeles, CA

**Skills and interests:** Parent support and networking; reducing trauma of repeated hospitalizations for families

**Experience:** Author of article for parents on coping with hospital system; leading training for health providers/teachers; starting or maintaining support groups

**Miftah H. MacNeil**  
562 East 19th Street  
Chico, CA 95928  
916 891-5865  
916 342-7107

**Child's disability:** Juvenile ceroid lipofucinosi; visual impairment;  
learning disability  
**Group affiliations:** ARC - Butte County - Respite Program Coordinator  
Pilot Parents  
FOCUS - Co-facilitator

**Health care facility where child receives majority of care:** University  
of California at San Francisco - San Francisco, CA

**Skills and interests:** Parent support; self-esteem building for  
families; collaborative programs for parents and professionals;  
education for disability awareness; holistic perspectives in care and  
education

**Experience:** Vice President for Parent Programs of Community Advisory  
Committee, Butte County SELPA (Special Education Local Plan Area); Co-  
facilitator, FOCUS; Member and past Chair, Pilot Parent Committee, ARC;  
public speaking; promoting legislation; starting or maintaining support  
groups; working with state health departments

**Profession:** Respite Program Coordinator, ARC - Butte County

**Ellen Parker**  
2437 D Street  
La Verne, CA 91750  
714 593-2827

**Child's disability:** Down Syndrome  
**Group affiliations:** Project COPE  
ARC

**Skills and interests:** Parent-to-parent support

**Experience:** Board Member, ARC; starting or maintaining support groups;  
working with state health departments

**Participation in ACCH Parent Network meetings (years):** 1986

**Lynn Powell**  
2700 Azusa, #155  
West Covina, CA 91792  
818 965-6473

**Child's disability:** Kidney disease  
**Group affiliation:** KIDS (Keys to Introducing Disabilities in Schools)  
**Health care facility where child receives majority of care:** UCLA  
Hospital - Los Angeles, CA  
**Skills and interests:** Conducting programs for children and teachers on  
disabilities; developing family support group  
**Experience:** Public speaking; leading training for health  
providers/teachers; starting or maintaining support groups; working  
with state health departments  
**Participation in ACCH Parent Network meetings (years):** 1986

**Florene Poyadue**  
535 Race Street, Suite 220  
San Jose, CA 95126  
408 288-5010  
408 251-1987

**Child's disability:** Down Syndrome  
**Group affiliation:** Parents Helping Parents, Inc. - Executive Director  
**Skills and interests:** Parent-to-parent support and education;  
parent/professional collaboration; statewide networks of parent groups  
across disabilities  
**Experience:** Public speaking; leading training for health  
providers/teachers; promoting legislation; starting or maintaining  
support groups; working with state health departments  
**Profession:** R.N.; Executive Director, Parents Helping Parents  
**Participation in ACCH Parent Network meetings (years):** 1985, 1986

**Karen Rath**  
2126 Lamer Street  
Burbank, CA 91504  
818 842-4575

**Child's disability:** Trisomy 4P; asthma; seizures; closed brain injury  
affecting motor abilities  
**Group affiliations:** Baseline  
P.O.N.D. (Parents of Near Drowners)  
**Skills and interests:** Networking with families of near-drowners  
**Profession:** Certified occupational therapist assistant  
**Participation in ACCH Parent Network meetings (years):** 1986

**Dale and Roswitha Robinson**  
1962 Asilomar Drive  
Oakland, CA 94611  
415 428-3382  
415 339-2769

**Children's disabilities:** Chnarcot-Marie-Tooth atrophy  
Mental retardation

**Group affiliation:** ARC

**Health care facility where children receive majority of care:**  
Children's Hospital - Oakland, CA

**Skills and interests:** Independent living skills; transition to  
independent living; networking with parents

**Experience:** Working with state health departments

**Participation in ACCH Parent Network meetings (years):** 1986

**Joan Stoddard**  
22 Pintail  
Irvine, CA 92714  
714 962-6332  
714 551-0729

**Child's disability:** Cerebral palsy; visual impairment; learning  
disability

**Group affiliations:** \*TASK (Team of Advocates for Special Kids) -  
Project Coordinator  
Community Advisory Council, Irvine Unified School  
District  
Legislative Action Network  
National Foundation of Wheelchair Tennis  
National Handicap Ski Association

**Health care facilities where child receives majority of care:**  
University of California - Irvine, CA; Stanford University - San Jose,  
CA

**Skills and interests:** Parent training in PL 94-142; advocacy for  
families with children with special needs; parent support

**Experience:** Public speaking; leading training for health  
providers/teachers; promoting legislation; starting or maintaining  
support groups; working with state health departments

**Profession:** Project Coordinator, \*TASK (Team of Advocates for Special  
Kids)

**Joanne Travers**  
872 Purdue Street  
Upland, CA 91786  
714 982-2804

**Child's disability:** Cerebral palsy (grandchild)  
**Group affiliation:** COPE (Community Outreach for Parent Education)  
**Skills and interests:** Parent-to-parent support; parent/professional collaboration  
**Experience:** Development and marketing of parent education project; public speaking; leading training for health providers/teachers  
**Profession:** Program Developer, Project COPE  
**Participation in ACCH Parent Network meetings (years):** 1983, 1984

**Dorothy Williams**  
834 22nd Street  
Santa Monica, CA 90403  
213 855-4431  
213 453-2274

**Child's disability:** Premature birth  
**Group affiliations:** Good Beginnings  
Parent Care  
**Health care facility where child receives majority of care:**  
Cedars-Sinai Medical Center - Los Angeles, CA  
**Experience:** Coordinates all parent support services to families with infants in the NICU; liaison with parents, social work, and medical staff; public speaking; leading training for health providers/teachers; starting or maintaining support groups  
**Profession:** Parent Counselor, Cedars-Sinai Medical Center  
**Participation in ACCH Parent Network meetings (years):** 1983

**Linda Wurzbach**  
111 Cantas Place  
San Ramon, CA 94583  
415 786-0901  
415 829-1852

**Child's disability:** Spina bifida and hydrocephalus; learning disability  
**Group affiliations:** Spina Bifida Association of San Francisco Bay Area  
COPE - Outreach to Parents  
**Health care facility where child receives majority of care:** Kaiser Hospital - Walnut Creek, CA  
**Skills and interests:** Special education issues for parents and professionals; collaboration among medical/educational professionals and parents  
**Experience:** State consultant for special education and medical issues; public speaking; leading training for health providers/teachers; starting or maintaining support groups;  
**Profession:** Parent specialist, State Department of Special Education  
**Participation in ACCH Parent Network meetings:** 1986

### COLORADO

**Paula Wray**  
20190 Amy Court  
Colorado Springs, CO 80908  
303 574-2345  
303 495-0270

**Child's disability:** Cleft lip and palate  
**Group affiliations:** National Cleft Palate Association  
Colorado Cleft Palate Association  
\*P.E.A.K. (Parents Education and Assistance for Kids)  
**Health care facility where child receives majority of care:** Children's Hospital, University of Colorado Health Sciences Center - Denver, CO  
**Skills and interests:** Parent training and information; insurance issues for cleft lip and palate  
**Experience:** Member, Board of Directors, National Cleft Palate Association; Past President, Colorado Cleft Palate Association; public speaking; leading training for health providers/teachers; promoting legislation; starting or maintaining support groups  
**Profession:** Occupational therapist; Information specialist, \*P.E.A.K.

## CONNECTICUT

**Ruth Norton**  
33 Old Bethel Road  
Newtown, CT 06470  
203 426-5453

**Child's disability:** Agenesis of the corpus callosum

**Group affiliation:** Learning Together  
Newtown Citizens with Alternate Needs  
Parent to Parent Network

**Health care facilities where child receives majority of care:** Yale New Haven Hospital - New Haven, CT; Newington Children's Hospital - Hartford, CT

**Skills and interests:** Parent-to-parent support and education; recreation activities and programs for children with special needs

**Experience:** Member, Advisory Board, Newington Children's Hospital Pediatric Rehabilitation and Training Center; Member, Parent/Professional Advisory Board, Newtown Special Education; Coordinator, summer program for children with special needs age 3 to 9; aide in PROBE program; public speaking; starting or maintaining support groups

**Participation in ACCH Parent Network meetings (years):** 1986

## DELAWARE

**Darlene Bonavita**  
640 Buckson Drive  
Dover, DE 19901  
302 734-3535  
302 734-5153

**Child's disability:** Cerebral palsy

**Group affiliation:** Parents for the Support of Handicapped Children

**Health care facility where child receives majority of care:** Alfred I. Dupont Hospital - Wilmington, DE

**Skills and interests:** Parent-to-parent support; editor of monthly newsletter for support group

**Experience:** Public speaking; promoting legislation; starting or maintaining support groups; working with state health departments

**Profession:** Secretary

**Emily Tarpley**  
9 Vassar Drive  
Newark, DE 19711  
302 738-6934

**Child's disability:** Turner's Syndrome  
**Group affiliation:** Human Growth Foundation, D.C. Chapter - Board Member and Treasurer  
**Health care facility where child receives majority of care:** Johns Hopkins University Hospital - Baltimore, MD  
**Skills and interests:** Creating network between genetic groups; prepared education program for teachers, parents and professionals about abnormal growth patterns and short stature; psychosocial aspects of short stature;  
**Experience:** Assisted in development of Iowa Health Care Guidelines for Families; public speaking; leading training for health providers/teachers; promoting legislation; starting or maintaining support groups  
**Profession:** Teacher

**DISTRICT OF COLUMBIA**

**Minna Newman Nathanson**  
2025 Eye Street Suite 1011  
Washington, DC 20006  
202 659-5136  
202 244-5803

**Child's disability:** Leukemia (deceased)  
**Group affiliation:** Candlelighters Childhood Cancer Foundation - Director of Publications  
**Skills and interests:** Medical and psychosocial information for parents and professionals; editor; early childhood development and education  
**Experience:** Public speaking; leading training for health providers/teachers; promoting legislation; starting or maintaining support groups  
**Profession:** Director of Publications, Candlelighters Foundation  
**Participation in ACCH Parent Network meetings (years):** 1983, 1984, 1985, 1986

**Marsha Parker**

3328 Martin Luther King Avenue S.E.  
Washington, DC 20032  
202 727-3866  
202 563-5971

**Child's disability:** Multiple handicaps

**Group affiliation:** \*Parents Reaching Out Service, Inc.  
Handicapped Infant Intervention Project  
Epilepsy Foundation

**Health care facility where child receives majority of care:** Children's Hospital National Medical Center - Washington, DC

**Skills and interests:** Parent-to-parent support; parent training and education

**Experience:** Public speaking; leading training for health providers/teachers; starting or maintaining support groups; working with state health departments

**Profession:** Director, Parent Resource Center, \*Parents Reaching Out Service

**FLORIDA**

**Joan Gebo**

3115 Coral Hills Drive #D-1  
Coral Springs, FL 33065  
305 755-7917

**Children's disabilities:** Bronchopulmonary dysplasia; near-SIDS;  
gastroesophageal reflux  
Bronchopulmonary dysplasia; epilepsy; T & B  
cell antibody deficiency

**Group affiliation:** SKIP of Florida - Director

**Skills and interests:** Parent networking and support

**Experience:** Starting or maintaining support groups

**Profession:** R.N., critical care

## GEORGIA

**Suz Anne Mitchell**  
2333 Parc Chateau Drive  
Lithonia, GA 30058  
404 482-6021

**Child's disability:** Moyamoya disease; achalasia  
**Health care facility where child receives majority of care:** Children's Medical Services - Atlanta, GA  
**Skills and interests:** Legislative issues for families of children with special needs  
**Profession:** R.N.; freelance artist

**Carla Putnam**  
1851 Ram Runway  
College Park, GA 30337  
404 761-2745  
404 941-3591

**Child's disability:** Learning disability  
**Group affiliation:** \*Parents Educating Parents - Director  
**Skills and interests:** Technical assistance to parent programs; parent support and training  
**Experience:** Leading training for health providers/teachers; promoting legislation; starting or maintaining support groups  
**Profession:** Director, \*Parents Educating Parents  
**Participation in ACCH Parent Network meetings (years):** 1986

## IDAHO

**Lorena Freund**  
3309 E. Pinehill Drive  
Coeur D'Alene, ID 83814  
208 667-6409  
208 667-8082

**Child's disability:** I-cell disease (deceased)  
**Group affiliation:** PROP (Parents Reaching to Other Parents)  
**Health care facility where child received majority of care:** Sacred Heart Hospital - Spokane, WA  
**Skills and interests:** Parent-to-parent support  
**Experience:** Public speaking; leading training for health providers/teachers; starting or maintaining support groups  
**Participation in ACCH Parent Network meetings (years):** 1986

## ILLINOIS

**Faye Manaster Eldar**  
8331 Kimball Avenue  
Skokie, IL 60076  
312 677-3796

**Child's disability:** Deaf-blind; cerebral palsy  
**Group affiliation:** Keshet: Jewish Families of Children with Special Needs - Co-President  
**Health care facility where child receives majority of care:** Children's Memorial Hospital - Chicago, IL  
**Skills and interests:** Parent outreach, training, information and referral; parent-to-parent support; preparing children for hospitalization; sensory impairments  
**Experience:** Public speaking; starting or maintaining support groups; working with state health departments  
**Participation in ACCH Parent Network meetings (years):** 1986

**Chuck Frame**  
5843 N. West Circle  
Chicago, IL 60631  
312 631-0038

**Child's disability:** C-5 quadriplegia  
**Health care facility where child receives majority of care:** Children's Memorial - Chicago, IL  
**Skills and interests:** Home care for medically fragile  
**Experience:** Public speaking; leading training for health providers/teachers; promoting legislation; starting or maintaining support groups; working with state health departments  
**Profession:** Printing  
**Participation in ACCH Parent Network meetings (years):** 1984

**James Green**  
1730 Hinman Road, #4A  
Evanston, IL 60201  
312 864-9533

**Child's disability:** Osteoarthritis; pernicious anemia  
**Skills and interests:** Film production; films and media materials about children with handicaps  
**Experience:** Developed media campaign for NICHCY; Member, Advisory Board, Easter Seals; public speaking; leading training for health providers/teachers  
**Profession:** Director Public Service Projects, Grey Chicago  
**Participation in ACCH Parent Network meetings (years):** 1985, 1986

**Audrey Lewis**  
1386 Glencoe Avenue  
Highland Park, IL 60035  
312 432-0594

**Child's disability:** Werdnig-Hoffmann disease  
**Group affiliation:** Families of Spinal Muscular Atrophy - President  
**Health care facilities where child receives majority of care** Shriners  
Hospital - Chicago, IL; Weiss Memorial - Chicago, IL;  
Children's Memorial - Chicago, IL  
**Skills and interests:** Increasing public awareness; parent to parent  
support  
**Experience:** Working on videotape of exercises for physically  
handicapped and able-bodied children  
**Participation in ACCH Parent Network meetings (years):** 1985

**Jennifer Paczynski**  
3133 N. George Street  
Franklin Park, IL 60131  
312 671-0088

**Child's disability:** Cancer (deceased)  
**Group affiliations:** Chicagoland Candlelighters  
Concerned Parents  
**Health care facility where child received majority of care:** Children's  
Memorial - Chicago, IL  
**Skills and interests:** Parent-to-parent support; early intervention  
**Experience:** Member of Parent Board, Lutheran General Hospital; public  
speaking  
**Profession:** R.N. at pediatric orthopedic hospital  
**Participation in ACCH Parent Network meetings (years):** 1983

**Audrey A. Simek**  
200 N. Riverwoods Road  
Lake Forest, IL 60045  
312 234-2412

**Children's disabilities:** Cystic fibrosis  
Cystic fibrosis  
Cystic fibrosis  
**Group affiliation:** Simek Memorial Counseling Center - Founder and  
Executive Director  
**Skills and interests:** Work with families of children with chronic  
illness; special interest in bereavement; psychosocial needs of  
families  
**Experience:** Public speaking; leading training for health  
providers/teachers; starting or maintaining support groups  
**Profession:** Psychotherapist  
**Participation in ACCH Parent Network meetings (years):** 1986

## **INDIANA**

### **Bobbie Fussichen**

502 Mt. Dora Lane  
Indianapolis, IN 46229  
317 897-5166

**Child's disability:** Cerebral palsy

**Group affiliations:** Cerebral Palsy Support Group - Founder and Vice President  
Parent Advisory Board - Methodist Hospital

**Health care facility where child receives majority of care:** Methodist Children's Hospital - Indianapolis, IN

**Skills and interests:** Advocacy for families of children with special needs; editor of newsletter

**Experience:** Member, Parent Advisory Board, Methodist Children's Hospital; public speaking; leading training for health providers/teachers; promoting legislation; starting or maintaining support groups; working with state health departments

**Profession:** R.N., psychiatric nurse clinician, Psychiatry Department, Methodist Hospital

### **Linda Hankins**

1511 Maria Lane  
Plainfield, IN 46168  
317 839-6201

**Child's disability:** Down Syndrome

**Group affiliation:** Indiana Task Force on Early Childhood Special Education - Parent Coordinator

**Health care facility where child receives majority of care:** James Whitcomb Riley Hospital for Children - Indianapolis, IN

**Skills and interests:** Working to mandate special education for 0-5 year olds; establish parent training center

**Experience:** Parent Coordinator, Indiana Task Force on Early Childhood Special Education; public speaking; leading training for health providers/teachers; promoting legislation; starting or maintaining support groups; working with state health departments

**Participation in ACCH Parent Network meetings (years):** 1986

**Joyce Jones**  
5005 Dickson Road  
Indianapolis, IN 40226  
317 542-0582

**Child's disability:** Spina bifida  
**Group affiliation:** Spina Bifida Association of Central Indiana -  
President  
**Health care facility where child receives majority of care:** James  
Whitcomb Riley Hospital for Children - Indianapolis, IN  
**Skills and interests:** Parent-to-parent support; newsletter editor  
**Experience:** Public speaking; promoting legislation

**Ruth Kimberley**  
128 E. Sycamore  
Vincennes, IN 47591  
812 882-0375

**Child's disability:** Hunter's Syndrome  
**Group affiliation:** Knox County Advocates for Special Kids - Founder  
**Health care facility where child receives majority of care:** James  
Whitcomb Riley Hospital for Children - Indianapolis, IN  
**Skills and interests:** Parent/professional collaboration; educating  
pediatricians  
**Experience:** Public speaking; promoting legislation; starting or  
maintaining support groups; working with state health departments

**Donna Lueking**  
Route 2 Box 117  
Sullivan, IN 47882  
812 382-4421

**Child's disability:** Juvenile diabetes  
**Group affiliation:** Juvenile Diabetes Support Group - President  
**Health care facilities where child receives majority of care:** Mary  
Sherman Hospital - Sullivan, IN; Methodist Children's Hospital -  
Indianapolis, IN  
**Skills and interests:** Parent-to-parent support; legislative reform for  
health care; collaboration between state agencies and parents  
**Experience:** President, Mary Sherman Hospital Foundation Board;  
Juvenile Diabetes Representative, Indiana National Voluntary Health  
Agencies Board; promoting legislation; working with state health  
departments  
**Participation in ACCH Parent Network meetings (years):** 1986

**Debra and James Morris**  
1141 E. Fairview Avenue  
South Bend, IN 46614  
219 232-3034  
219 288-1079

**Child's disability:** Physical, visual and mental handicaps  
**Group affiliation:** Parents Helping Parents - Founders  
**Health care facility where child receives majority of care:** St. Joseph's Medical Center - South Bend, IN  
**Skills and interests:** Long term medical financial planning; identification of services for families of children with special needs; legislation for children with handicaps; computer adaptations for special needs  
**Experience:** Promoting legislation; starting or maintaining support groups; working with state health departments

**Donna Olsen**  
2107 East 65th  
Indianapolis, IN 46220  
317 257-8683

**Children's disabilities:** Cystic fibrosis  
Cystic fibrosis  
**Group affiliation:** Parent Advisory Board - Methodist Children's Hospital - Chairperson  
**Health care facility where children receive majority of care:** Methodist Children's Hospital - Indianapolis, IN  
**Skills and interests:** Parent/professional collaboration; increasing awareness of needs of children with chronic conditions in hospital, school, and community  
**Experience:** Chairperson, Parent Advisory Board, Methodist Hospital; public speaking; leading training for health providers/teachers; starting or maintaining support groups; working with state health departments  
**Participation in ACCH Parent Network meetings (years):** 1984, 1985, 1986

**Beverly Preske**

2835 W. Booneville-New Harmony Road  
Evansville, IN 47712  
812 963-9010

**Child's disability:** Cerebral palsy

**Group affiliations:** Concerned Parent of the Retarded and Handicapped -  
President  
Parents and Professionals Advocating for the  
Handicapped - President  
TOUCH (To Our Understanding of Children with  
Handicaps) - Vice President

**Health care facility where child receives majority of care:** Deaconess  
Hospital - Evansville, IN

**Skills and interests:** Developed training program for parents; parent-  
to-parent support

**Experience:** Public speaking; leading training for health  
providers/teachers; promoting legislation; starting or maintaining  
support groups; working with state health departments

**Profession:** United Cerebral Palsy of Indiana

**Connie Rahe**

RR #1 Box 394  
Muncie, IN 47302  
317 358-4813

**Child's disability:** Cystic fibrosis

**Group affiliation:** Cystic Fibrosis Parent Support Group

**Health care facility where child receives majority of care:** Methodist  
Children's Hospital - Indianapolis, IN

**Skills and interests:** Parent-to-parent support

**Experience:** Public speaking; leading training for health  
providers/teachers; promoting legislation; starting or maintaining  
support groups; working with state health departments

**Profession:** Special education resource teacher

**Pat Rieger**

2110 E. 65th Street  
Indianapolis, IN  
317 257-6598

**Child's disability:** Duchenne's Muscular Dystrophy

**Group affiliation:** Muscular Dystrophy Support Group - Founder

**Health care facility where child receives majority of care:** Methodist  
Children's Hospital - Indianapolis, IN

**Skills and interests:** Parent-to-parent support

**Experience:** Member, Parent Advisory Board, Methodist Children's  
Hospital; public speaking; leading training for health providers/  
teachers; starting or maintaining support groups

**Participation in ACCH Parent Network meetings (years):** 1985

**Connie L. Shella**  
7957 Dartmouth Road  
Indianapolis, IN 46260  
317 846-4206  
317 253-2769

**Child's disability:** Diabetes; epilepsy  
**Group affiliation:** American Diabetes Association  
**Health care facility where child receives majority of care:** Methodist Children's Hospital - Indianapolis, IN  
**Skills and interests:** Diabetes education; updating diabetes education for families; parent/professional collaboration; prenatal classes for diabetics  
**Experience:** Member, Parent Advisory Board, Methodist Children's Hospital; Executive Board Member, American Diabetes Association; leading training for health providers/teachers; starting or maintaining support groups; working with state health departments  
**Profession:** R.N.; Diabetes educator  
**Participation in ACCH Parent Network meetings (years):** 1985, 1986

**Carol Whetsel**  
442 E. State Street  
Pendleton, IN  
317 778-4192

**Child's disability:** Cystic fibrosis  
**Group affiliation:** Cystic Fibrosis Parent Support Group  
**Skills and interests:** Parent-to-parent support; organized family support conference  
**Experience:** Public speaking; leading training for health providers/teachers; promoting legislation; starting or maintaining support groups  
**Participation in ACCH Parent Network meetings (years):** 1985

## **IOWA**

### **Julie Beckett**

2420 D Avenue NE  
Cedar Rapids, IA 52402  
319 353-6173  
319 362-0978

**Child's disability:** Post encephalitis; ventilator assisted  
**Group affiliation:** SKIP of Iowa - Director  
**Health care facility where child receives majority of care:** St. Luke's Methodist Hospital - Cedar Rapids, IA  
**Skills and interests:** Funding for home care for medically fragile  
**Experience:** Assisted in development of Iowa Health Care Guidelines for Families; Member, Governor's Planning Council on Developmental Disabilities; participates on Maternal and Child Health Advisory Council; Associate Director for Consumer Affairs, National Maternal and Child Health Resource Center, University of Iowa Law School; Parent Consultant, Parent-Educator Partnership Project; Vice Chairperson, Task Force on Technology Dependent Children, Department of Health and Human Services; public speaking; leading training for health providers/teachers; promoting legislation; starting or maintaining support groups; working with state health, education and social service departments  
**Participation in ACCH Parent Networking meetings (years):** 1985, 1986

### **Carla Lawson**

33 N. 12th Street  
P.O. Box 1151  
Fort Dodge, IA 50501  
515 576-5870

**Children's disabilities:** Werdnig-Hoffmann disease  
Werdnig-Hoffmann disease (deceased)  
**Group affiliations:** Iowa Exceptional Parent Center - Director  
**Health care facility where child receives majority of care:** University Hospital - Iowa City, IA  
**Skills and interests:** Parent education and training about PL 94-142; develops workshops for health care professionals; consults and develops resources for parent center at University Hospital  
**Experience:** Public speaking; leading training for health providers/teachers; promoting legislation; starting or maintaining support groups; working with state health departments  
**Profession:** Director, Iowa Exceptional Parent Center  
**Participation in ACCH Parent Network meetings (years):** 1983, 1984, 1986

**Jule Reynolds**  
1922 E 12th  
Des Moines, IA 50316  
515 263-9247

**Child's disability:** Cerebral palsy; seizures  
**Group affiliations:** Special Care Parents - Chairperson  
\*Iowa Pilot Parents

**Health care facilities where child receives majority of care:** Iowa Methodist Medical Center - Des Moines, IA; Blank Children's Hospital - Des Moines, IA

**Skills and interests:** Technical assistance facilitator for department of education; parent consultant for education department

**Experience:** Parent Consultant, Department of Education; public speaking; leading training for health providers/teachers; starting or maintaining support groups; working with state health departments

### KANSAS

**Kathy Johnson**  
4445 N.W. 52nd Terrace  
Topeka, KS 66618  
913 267-4270  
913 288-2114

**Child's disability:** Cerebral palsy

**Group affiliation:** \*Families Together - Resource Coordinator

**Health care facility where child receives majority of care:** Kansas University Medical Center - Kansas City, KS

**Skills and interest:** Editor of newsletter; family enrichment weekends; coordinates Count Me In Puppets for parent training center

**Experience:** Member, Citizens Advisory Council on Preschool Handicapped; public speaking; leading training for health providers/teachers; promoting legislation; starting or maintaining support groups; working with state health departments

**Profession:** Resource Coordinator, \*Families Together

**Participation in ACCH Parent Network meetings (years):** 1986

## **KENTUCKY**

### **Lavonna King**

5974 Rich Pond Road  
Bowling Green, KY 42101  
502 781-6111  
502 843-6191

**Child's disability:** Cerebral palsy; multiple handicaps  
Cerebral palsy; multiple handicaps

**Group affiliation:** Kentucky Commission for Handicapped Children -  
Chairperson

**Health care facility where children receive majority of care:** Jewish  
Hospital, Louisville, KY

**Skills and interests:** Education needs of children with special needs;  
parent-to-parent support

**Experience:** Chairperson, Kentucky Commission for Handicapped Children;  
Past Chairperson, United Cerebral Palsy Association, South Central  
Kentucky; public speaking; promoting legislation

**Profession:** Bank operations officer

### **Carmen Yates**

1113 Chinoe Road  
Lexington, KY 40502  
606 269-1349

**Child's disability:** Cystic fibrosis

**Group affiliations:** Kentucky Cystic Fibrosis Services, Inc. -  
President

RISE (Resource Information and Support Exchange)

**Health care facility where child receives majority of care:** University  
of Kentucky Medical Center - Lexington, KY

**Skills and interests:** Parent-to-parent support; access to information

**Experience:** Member, Health Information Council; public speaking;  
starting or maintaining support groups; working with state health  
departments

## LOUISIANA

**Kathy and Dave Duff**  
P.O. Box 2716  
Lafayette, LA 70502-2716  
318 237-6948

**Child's disability:** Cerebral palsy

**Group affiliation:** Parents of Special Children - Secretary and President

**Health care facility where child receives majority of care:** Children's Hospital - New Orleans, LA

**Skills and interests:** Parent-to-parent support

**Experience:** Starting or maintaining support groups; working with state health departments

**Participation in ACCH Parent Network meetings (years):** 1984

## MAINE

**Marie Lowell**  
RFD #1 Box 1020  
Buckfield, ME 04220  
207 336-2657  
207 336-2411

**Child's disability:** Down Syndrome

**Group affiliation:** The Child Health Center - Coordinator of Child Development Program

**Health care facility where child receives majority of care:** The Child Health Center - Norway, ME

**Skills and interests:** Identification and education of preschool children with special needs; outreach to parents and professionals; encouraging early referrals and intervention by professionals

**Experience:** Member, Governor's Advisory Board for the Bureau of Children with Special Needs; Chairperson, Local Coordinating Committee for Preschool Project; Chairperson, Local School Board; working with State Division of Maternal and Child Health; public speaking; leading training for health providers/teachers

**Profession:** Coordinator of Child Development Program, The Child Health Center

**Sherry S. Pierce**

Fairview Drive  
P.O. Box 273  
Fryeburg, ME 04037  
207 935-2092  
207 935-3616

**Child's disability:** Hypsarrhythmia; mixed seizure disorder

**Health care facility where child receives majority of care:**

Massachusetts General Hospital - Boston, MA

**Skills and interests:** Respite care; parent/professional collaboration; parent advocacy

**Experience:** Member, Governor's Advisory Council for the Bureau of Children with Special Needs; public speaking; promoting legislation; working with state health departments

**Profession:** Sales manager for forest products company

**Participation in ACCH Parent Network meetings (years):** 1986

**Jan Waite-Austin**

36 High Street  
Bath, ME 04530  
207 389-1683

**Child's disability:** Cerebral palsy

**Group affiliations:** \*SPIN (Special Needs Parent Information Network) -  
- Parent Information Specialist  
Project Search - Chair, Local Coordinating  
Committee

**Health care facility where child receives majority of care:** Boston  
Children's Hospital - Boston, MA

**Skills and interests:** Parent training in PL 94-142; help initiate  
parent support groups; help locate resources for families of children  
with special needs; family support issues

**Experience:** Chair, Local Coordinating Committee, Project Search;  
Former Parent Representative, Interdepartmental Committee for the Care  
of Preschool Handicapped Children; public speaking; leading training  
for health providers/teachers; starting or maintaining support groups;  
working with state health departments

**Profession:** Parent Information Specialist, \*SPIN

**Participation in ACCH Parent Network meetings (years):** 1986

## MARYLAND

### **Sandy Reckeweg**

3957 Wintergreen Place  
Waldorf, MD 20601  
301 843-3937

**Child's disability:** Central hypoventilation syndrome; collapsible airway syndrome

**Group affiliations:** SKIP - Parent liaison  
National Association for Home Care  
Parents of Chronically Ill Children - Co-founder

**Health care facility where child receives majority of care:** Children's National Medical Center - Washington, DC

**Skills and interests:** Parent support and advocacy; writing directory of resources, services and helpful hints for families of technology assisted/medically fragile children

**Experience:** Parent Consultant, National Association for Home Care; public speaking; leading training for health providers/teachers; starting or maintaining support groups; working with state health departments

**Profession:** Mortgage loan officer

**Participation in ACCH Parent Network meetings (years):** 1986

### **Amita Sarin**

7915 Declaration Lane  
Potomac, MD 20854  
301 299-5606

**Child's disability:** Cerebral palsy; blind; mental retardation

**Group affiliation:** Vision Parents Support Group

**Health care facility where child receives majority of care:** Children's Hospital National Medical Center - Washington, DC

**Skills and interests:** Training health professionals about the needs of families; ethical issues in treatment

**Experience:** Member, Ethics Forum, Children's Hospital National Medical Center; public speaking; leading training for health providers/teachers

**Claudia Segal**  
1657 Yale Place  
Rockville MD 20850  
301 762-4858

**Child's disability:** Cerebral palsy; seizures  
**Health care facility where child receives majority of care:** Children's Hospital National Medical Center - Washington, DC  
**Skills and interests:** Parent-to-parent support; networking at the state and national level  
**Experience:** Member, Committee for Special Needs, Jewish Community Center; leading training for health providers/teachers; starting and maintaining support groups; working with state health departments  
**Participation in ACCH Parent Network meetings (years):** 1986

**Karen Shannon**  
216 Newport Drive  
Severna Park, MD 21146  
301 647-0164

**Child's disability:** Respiratory; hearing impairment  
**Group affiliation:** SKIP - Founder and National Executive Director  
**Skills and interests:** Developing educational materials for families and professionals caring for children dependent on technology; public awareness  
**Experience:** Member, Maryland work group to develop guidelines for PL 99-457; awarded Congressional fellowship to work on Capitol Hill; public speaking; leading training for health providers/teachers; promoting legislation; starting or maintaining support groups; working with state health and education departments  
**Participation in ACCH Parent Network meetings (years):** 1984, 1985, 1986

## **MASSACHUSETTS**

### **Betsy Anderson**

9 Davis Avenue  
Brookline, MA 02146  
617 482-2915  
617 566-5998

**Child's disability:** Spina bifida

**Group Affiliations:** \*Federation for Children with Special Needs  
Massachusetts Spina Bifida Association

**Skills and interests:** Parent/professional collaboration;  
family-centered programs; parent training in PL 94-142; health care  
financing

**Experience:** Parent Advisory Committee, Boston Children's Hospital;  
Chair, Consumer Concerns Committee, New England Regional Genetics  
Group; Congressional Committee on Health Care Financing for Technology  
Dependent Children; public speaking; leading training for health  
providers/teachers; promoting legislation; starting or maintaining  
support groups; working with state health departments

**Profession:** Director of Health Issues, \*Federation for Children with  
Special Needs; Director, CAPP Project (Collaboration Among Parents and  
Health Professionals)

**Participation in ACCH Parent Network meetings (years):** 1984, 1985,  
1986

### **Priscilla Bradway**

18 Chandler Circle  
Andover, MA 01810  
617 475-0902

**Child's disability:** Cleft lip and palate; hemifacial microsomia

**Skills and interest:** Parent support group leader; sibling support and  
workshops for teachers

**Experience:** Member, Parent Advisory Committee, Boston Children's  
Hospital; public speaking; leading training for health  
providers/teachers; starting or maintaining support groups

**Participation in ACCH Parent Network meetings (years):** 1985, 1986

**Betty Burton**  
52 Edgell Street  
Gardner, MA 01440  
617 632-7783

**Child's disability:** Toxoplasmosis  
**Group affiliation:** Toxoplasmosis Foundation - Founder  
**Health care facilities where child receives majority of care:**  
University of Massachusetts Medical Center - Worcester, MA;  
Massachusetts Eye and Ear Infirmary - Boston, MA; Massachusetts General  
Hospital - Boston, MA  
**Skills and interests:** Parent education; parent-to-parent support group  
organizer; early intervention  
**Experience:** Public speaking; leading training for health  
providers/teachers; promoting legislation; starting or maintaining  
support groups; working with state health departments  
**Participation in ACCH Parent Network meetings:** 1985

**Mr. and Mrs. Charles Fiske**  
70 Sewall Avenue  
Brookline, MA 02146  
617 566-3430

**Child's disability:** Organ transplant  
**Group affiliations:** The Family Inn - Founder  
New England Organ Bank  
**Skills and interests:** Promoting legislation; developing housing for  
families of hospitalized children  
**Experience:** Starting The Family Inn - a house for families to stay in  
while their children await organ transplants; public speaking; leading  
training for health providers/teachers; starting or maintaining support  
groups; working with state health departments

**Brooke Heraty**  
24 Chenery Terrace  
Belmont, MA 02178  
617 484-1762

**Child's disability:** Cerebral palsy  
**Group affiliation:** Mothers Support Group  
**Health care facility where child receives majority of care:** Children's  
Hospital - Boston, MA  
**Skills and interests:** Parent-to-parent support; education issues  
**Experience:** Promoting legislation; starting or maintaining support  
groups  
**Participation in ACCH Parent Network meetings:** 1985

**Patricia Krug**  
21 Vine Rock Street  
Dedham, MA 02026  
617 326-4775  
617 326-5537

**Child's disability:** Neurofibromatosis  
**Group affiliation:** National Neurofibromatosis Foundation - Director of Operations, MA Chapter  
**Health care facilities where child receives majority of care:** Massachusetts General Hospital - Boston, MA; Boston Children's Hospital - Boston, MA  
**Skills and interests:** Fund raising; increasing public awareness; support for families  
**Experience:** Officer with Massachusetts Chapter of the National Neurofibromatosis Foundation for 7 years

**Janet Miller**  
737 Bay Road Box 7  
Hamilton, MA 01936  
617 468-1006

**Child's disability:** Spina bifida and hydrocephalus  
**Group affiliation:** Massachusetts Spina Bifida Association  
**Health care facility where child receives majority of care:** New England Medical Center - Boston, MA  
**Skills and interests:** Parent-to-parent support; coping and medical management; bracing, equipment resources, and accessible environments; church involvement  
**Experience:** Advisory Board, Adaptive Environments Center; hospital internships; brace shop work; public speaking; leading training for health providers/teachers  
**Profession:** Rehabilitation counselor  
**Participation in ACCH Parent Network meetings (years):** 1985

**Barbara Popper**  
31 Wilshire Park  
Needham, MA 02192  
617 444-3877

**Child's disability:** Paralysis of facial nerve  
**Group affiliation:** Children in Hospitals - President  
**Skills and interests:** Support for families in hospitals; psychosocial policies and programs in hospitals; parent/professional collaboration at state level  
**Experience:** Member, Parent Advisory Board, Boston Children's Hospital; developed Consumer Directory of Hospital Policies in Massachusetts; public speaking; leading training for health providers/teachers; promoting legislation; starting or maintaining support groups; working with state health departments  
**Participation in ACCH Parent Network meetings (years):** 1985, 1986

**Margie Saphier**  
56 Bellows Hill Road  
Carlisle, MA 01741  
617 369-4467

**Child's disability:** Hearing impairment  
**Group affiliations:** Children in Hospitals - Newsletter Editor  
\*Federation for Children with Special Needs  
**Skills and interests:** Parent advocacy in health care settings  
**Experience:** Member, Parent Advisory Board, Massachusetts General Hospital; public speaking; leading training for health providers/teachers; promoting legislation; starting or maintaining support groups; working with state health departments  
**Participation in ACCH Parent Network meetings (years):** 1985

**Janet Vohs**  
312 Stuart Street  
Boston, MA 02116  
617 482-2915  
617 731-3410

**Child's disability:** Cerebral palsy  
**Group affiliation:** \*Federation for Children with Special Needs  
**Skills and interests:** Parent training in care management and coordination of care; community supports for families with special needs; early education policy  
**Experience:** Public speaking; leading training for health providers/teachers; promoting legislation; starting or maintaining support groups; working with state health departments  
**Profession:** \*Federation for Children with Special Needs; Assistant Director, CAPP Project (Collaboration Among Parents and Health Professionals)  
**Participation in ACCH Parent Network meetings (years):** 1986

**Nora Wells**

9 Washington Street  
Lexington, MA 02173  
617 482-2915  
617 862-2680

**Child's disability:** Cerebral palsy

**Group affiliation:** \*Federation for Children with Special Needs

**Health care facilities where child receives majority of care:**

Children's Hospital - Boston, MA; New England Medical Center - Boston, MA

**Skills and interests:** Promoting legislation on health care financing; parent/professional collaboration

**Experience:** Member, Parent Advisory Board, Boston Children's Hospital; Parent Advisory Board, New England Medical Center; public speaking; leading training for health providers/teachers; promoting legislation; starting or maintaining support groups; working with state health departments

**Profession:** Consultant, CAPP Project (Collaboration Among Parents and Health Professionals), \*Federation for Children with Special Needs

**Participation in ACCH Parent Network meetings (years):** 1983, 1985, 1986

**Joanne Buzzo Wilhelm**

7 Helena Drive  
Tyngsboro, MA 01879  
617 649-7573

**Child's disability:** Degenerative neuromuscular disease (deceased)

**Skills and interests:** Education needs of 0-3 year olds; parent education and support; collaboration with medical and education professionals

**Participation in ACCH Parent Network meetings (years):** 1985, 1986

## **MICHIGAN**

### **Mark Chesler**

University of Michigan  
Dept of Sociology  
4028 LSA Building  
Ann Arbor, MI 48104  
313 747-3654  
313 764-7487

**Child's disability:** Cancer

**Group affiliation:** Candlelighters Childhood Cancer Foundation -  
National President

**Skills and interests:** Parent/professional collaboration; development  
of national parent support groups

**Experience:** Public speaking; leading training for health  
providers/teachers; starting or maintaining support groups; working  
with state health departments

**Profession:** Professor of Sociology, University of Michigan

**Participation in ACCH Parent Network meetings (years):** 1983, 1984

### **Yvonne De Paepe**

1105 S. Clinton Avenue  
St. Johns, MI 48879  
517 224-4383

**Child's disability:** Severe physical and mental impairment

**Group affiliation:** Clinton County Support Group for Parents with  
Handicapped Children - Founder

**Health care facility where child receives majority of care:** University  
of Michigan Hospital - Ann Arbor, MI

**Skills and interests:** Parent-to-parent support; state legislative  
issues

**Experience:** Promoting legislation; starting or maintaining support  
groups; working with state health departments

**Profession:** Driver for school district

**Connie Fischer**

44 John Ball Park Drive NW  
Grand Rapids, MI 49504  
616 458-8744

**Child's disability:** Trisomy 18

**Group affiliations:** Mercy Respite Care Center - 1st President  
SKIP of Michigan  
Foundation for Hospice and Home Care  
Families and Friends of Disabled Persons

**Health care facility where child receives majority of care:**

Butterworth Hospital - Grand Rapids, MI

**Skills and interests:** Home care and insurance for medically fragile children; education and awareness of family needs and support in long term chronic, catastrophic illness in children; family support and advocacy for families with developmentally disabled children; promoting support of continuum of respite services for families with developmentally disabled children; insurance issues

**Experience:** Public speaking; promoting legislation; starting or maintaining support groups; working with state health departments

**Profession:** R.N.

**Carolyn Fowler**

3075 Shoshone SW  
Grandville, MI 49418  
616 457-5380  
616 534-3568

**Children's disabilities:** Multiple congenital anomalies  
Down Syndrome; blind; hearing impairment

**Group affiliations:** ARC  
Michigan Protection and Advocacy Service

**Health care facility where children receive majority of care:**

Butterworth Hospital - Grand Rapids, MI

**Skills and interests:** Advocacy and assistance for families; home care; job advocacy for developmentally disabled

**Experience:** Serves on advisory boards for Developmental Disabilities Services, Community Mental Health, and \*CAUSE (Citizens Alliance to Uphold Special Education); public speaking; promoting legislation; starting or maintaining support groups; working with state health departments

**Profession:** Case manager, State Protection and Advocacy Services

**Participation in ACCH Parent Network meetings (years):** 1983, 1984

**Patricia and John Hanley**

1224 Berten Street  
Lansing, MI 48910  
517 372-8094

**Children's disabilities:** Cerebral palsy; visual impairment

Cerebral palsy; visual impairment

**Group affiliations:** United Cerebral Palsy of Lansing - Treasurer  
SEPAC (Special Education Parent Advisory  
Committee)

The Parent Support Group

**Skills and interests:** Parent-to-parent support; advocacy for families  
with children with special needs; legislation issues

**Experience:** Treasurer, United Cerebral Palsy of Lansing; Chairperson,  
PTA, Center Program School, Lansing School District; public speaking;  
promoting legislation; starting or maintaining support groups; working  
with state health departments

**Beverly McConnell**

2990 Syckelmoone  
Trenton, MI 48183  
313 557-5070  
313 675-7593

**Child's disability:** Cerebral palsy; apnea; epilepsy

**Group affiliation:** \*United Cerebral Palsy Association of Metropolitan  
-Detroit - Training Coordinator

Northwestern Guidance Respite Care Program

Community Mental Health Developmental Disabilities  
Advisory Committee

County Regional Interagency Coordinating  
Committee

**Health care facility where child receives majority of care:** Children's  
Hospital of Michigan - Detroit, MI

**Skills and interests:** Promoting advocacy skills for parents of  
children with special needs; training parents on PL 94-142

**Experience:** Founder, Parent Advisory Council, Northwestern Guidance  
Respite Care Program; Past President, Early Intervention Parent  
Advisory Council; Member, ARC; public speaking; leading training for  
health providers/teachers; promoting legislation; starting or  
maintaining support groups

**Profession:** Training Coordinator, Parents Training Parents Project,  
\*United Cerebral Palsy Association of Metropolitan Detroit

**Deborah Russell**  
9785 North 30th Street  
Richland, MI 47083  
616 629-4985

**Child's disability:** Trachealstenosis  
**Group affiliations:** SKIP of Michigan  
\*CAUSE (Citizens Alliance to Uphold Special  
Education)

**Health care facility where child receives majority of care:** Children's  
Hospital of Michigan - Detroit, MI

**Skills and interests:** Insurance and home care needs for medically  
fragile; support for families

**Experience:** Consumer representative to Upjohn; works with  
Developmental Disabilities Council; planning family conference at  
Michigan State University; public speaking; promoting legislation;  
starting or maintaining support groups; working with state health  
departments

**Paula Vander Meulen**  
513 Carrier N.E.  
Grand Rapids, MI 49505  
616 456-3818  
616 456-1897

**Child's disability:** Severe congenital physical anomalies

**Group affiliations:** ARC of Kent County  
Parents and Friends of Disabled

**Health care facility where child receives majority of care:** University  
of Michigan - Ann Arbor, MI

**Skills and interest:** Comfort and psychotherapy with families and  
groups; crisis counseling for health professionals

**Experience:** ACCH editorial board; parent resource to staff in  
pediatric neurology and orthopedics, University of Michigan Hospital;  
consultant to planning division for state CCS; public speaking; leading  
training for health providers/teachers; starting or maintaining support  
groups; working with state health departments

**Profession:** Social worker

**Participation in ACCH Parent Network meetings (years):** 1983, 1984

**Connie Wells**  
65646 Middle Colon Road  
Burr Oak, MI 49030  
616 489-5385

**Children's disabilities:** Epilepsy; learning disability  
Central apnea; ventricular tachycardia;  
seizures; hypothermia  
Apnea; epilepsy

**Group affiliations:** SKIP of Michigan  
Apnea Support Group

**Health care facility where children receive majority of care:**  
University of Michigan - Ann Arbor, MI

**Skills and interests:** Insurance coverage for home health care;  
educational advocacy

**Experience:** Public speaking; leading training for health  
providers/teachers; promoting legislation; starting or maintaining  
support groups; working with state health departments

#### **MINNESOTA**

**LuAnn Jelinek**  
140 W. Richmond Street South  
St. Paul, MN 55075  
612 455-3903

**Children's disabilities:** Cerebral palsy; hyperactive  
Profound mental retardation; seizures; cleft  
lip and palate; crying disorder; severe  
stomach disorder

**Skills and interests:** Respite care; conducts training sessions for  
respite care and for foster care parents; spiritual needs of  
handicapped children

**Experience:** Public speaking; leading training for health  
providers/teachers; promoting legislation; starting or maintaining  
support groups; working with state health departments

**Profession:** Social worker

**Participation in ACCH Parent Network meetings (years):** 1986

**Jean Mandeville**  
2 West Street  
Albans Road  
Hopkins, MN 55343  
612 936-0946

**Child's disability:** Osteogenesis imperfecta  
**Group affiliations:** Osteogenesis Imperfecta Association  
\*PACER (Parent Advocate Coalition for Education  
-Rights)  
Minnesota Human Genetics League

**Skills and interests:** Resources for parents; parent/professional  
collaboration; research in genetics

**Experience:** President, Minnesota Osteogenesis Imperfecta Association;  
President, Minnesota Human Genetics League; developed written and audio  
visual materials on osteogenesis imperfecta; promoting legislation;  
worked to increase research funds for osteogenesis imperfecta

**Participation in ACCH Parent Network meetings (years):** 1986

**Virginia Richardson**  
4044 Oakland Avenue South  
Minneapolis, MN 55407  
612 927-2966  
612 822-3464

**Child's disability:** Mental retardation; epilepsy  
**Group affiliation:** \*PACER (Parent Advocate Coalition for Education  
-Rights) - Parent Training Coordinator

**Skills and interests:** Parent training in PL 94-142

**Profession:** Parent Training Coordinator, \*PACER

**Linda Rother**  
782 Sunset Drive  
Eagan, MN 55121  
612 454-3537

**Children's disabilities:** Hearing impairment; learning disability  
Seizures; developmental delays; mental  
retardation; migraines  
Ataxia; seizures; hyperflexia; hypotonia;  
infantile apnea; developmental delays

**Skills and Interests:** Parent/professional collaboration; early  
education for handicapped children; developing computer software for  
learning disabled

**Experience:** Public speaking; leading training for health  
providers/teachers; promoting legislation; starting or maintaining  
support groups; working with state health departments

**Profession:** R.N.

**Participation in ACCH Parent Network meetings (years):** 1986

## **MISSISSIPPI**

**Kathy Odle**

Route 1, Box 119  
New Site, MS 38859  
601 728-5121

**Children's disabilities:** Neuro Axon I Dystrophy  
Neuro Axon I Dystrophy

**Group affiliation:** North Mississippi Coalition for Handicapped  
Residents - President  
Children's Medical Program Parent Advisory  
Committee - Chairperson

**Health care facility where children receives majority of care:** Blake  
Clinic, Children's Medical Program - Mississippi State Board of Health

**Skills and interests:** Parent-to-parent support; respite and home care  
services; access to information for parents; parent/professional  
collaboration

**Experience:** Member, Children's Medical Program Advisory Board;  
Newsletter Editor, North Mississippi Coalition for Handicapped  
Residents; public speaking; leading training for health  
providers/teachers; promoting legislation; starting or maintaining  
support groups; working with state health departments

**Profession:** School attendance officer

**Participation in ACCH Parent Network meetings (years):** 1986

## **MISSOURI**

**Judy Shaw**

716 East High Street  
Jefferson City, MO 65101  
314 635-2511

**Child's disability:** Leukemia

**Group affiliation:** Candlelighters Childhood Cancer Foundation

**Health care facility where child receives majority of care:** Cardinal  
Glennon Memorial Hospital for Children - St. Louis, MO

**Skills and interests:** Parent-to-parent support; public education

**Experience:** Public speaking; leading training for health  
providers/teachers; starting or maintaining support groups; working  
with state health departments

**Participation in ACCH Parent Network meetings (years):** 1983

**NEBRASKA**

**B.J. and Chris Reed**  
113 South 50th Avenue  
Omaha, NE 68132  
402 554-2625  
402 556-5509

**Child's disability:** Short bowel syndrome  
**Health care facilities where child receives majority of care:**  
Children's Memorial Hospital - Omaha, NE; Swanson Center for Nutrition  
- Omaha, NE  
**Skills and interests:** Parent-to-parent support; insurance issues for  
families with children with chronic illness  
**Experience:** Public speaking; promoting legislation; starting or  
maintaining support groups; working with state health departments  
**Profession:** Professors of Public Administration

**Brenda Sutton**  
7616 Bauman Avenue  
Omaha, NE 68122  
402 346-5220  
402 571-4862

**Child's disability:** Down Syndrome  
**Group affiliation:** Pilot Parents - Program Coordinator  
**Health care facility where child receives majority of care:** University  
Medical Center - Omaha, NE  
**Skills and interests:** Providing information and support to families at  
time of diagnosis; work with hospitals to refer families to Pilot  
Parents  
**Experience:** Public speaking; leading training for health  
providers/teachers; starting or maintaining support groups; working  
with state health departments  
**Profession:** Coordinator, Pilot Parents

**NEVADA**

**Joanne C. Brownlie**  
2221 McCoig Avenue  
Las Vegas, NV 89119  
702 736-8555  
702 736-8302

**Children's disabilities:** Down Syndrome  
Bilateral cleft lip and palate; learning disabilities

**Group affiliations:** CHANCE (Coalition for Handicapped Children's Education) - Coordinator, Parent Advisory Liaison Project  
South Nevada Down Syndrome Organization  
Special Education Parent Advisory Committee

**Skills and interests:** Information and assistance for families of children and youth with special needs from birth through 21 years; linking parents with other parents and community services; liaison between families and the school district or community agencies

**Experience:** Past President, South Nevada Down Syndrome Organization; Representative, Special Education Parent Advisory Committee; public speaking; leading training for health providers/teachers; promoting legislation; starting or maintaining support groups; working with state health departments

**Profession:** Coordinator, Parent Advisory Liaison Project, CHANCE

**Deborah Davis**  
3015 Heights Drive  
Reno, NV 89503  
702 747-5392  
702 747-5110

**Children's disabilities:** Congenital fibertype disproportion  
Congenital fibertype disproportion  
**Group affiliations:** CHANCE (Coalition for Handicapped Children's  
Education) - Project Coordinator, Parents Helping  
Parents Project  
N-STEP (Nevada Specially Trained Effective  
Parents) - Information Coordinator  
**Health care facility where children receive majority of care:** Special  
Children's Clinic - Reno, NV  
**Skills and interests:** Support for families; training on PL 94-142;  
helping families learn coping skills; parent/professional collaboration  
**Experience:** Parent Member, State Special Education Advisory Committee;  
Member, Standards Revision Task Force; Member, Board of Directors, Very  
Special Arts; Advisory Board Member, HAPPY (Home Activity Program for  
Parents and Youth); Member, Advisory Committee, Member, Parent  
Auxiliary, PACEER; Member, Board of Directors, Special Children's  
Clinic; public speaking; leading training for health  
providers/teachers; promoting legislation; starting or maintaining  
support groups; working with state health departments  
**Profession:** Project Coordinator, Parents Helping Parents Project,  
CHANCE; Information Coordinator, N-STEP

#### NEW HAMPSHIRE

**Judy Lindquist**  
11 East Dunstable Road  
Nashua, NH 03060  
603 888-7706

**Child's disability:** Premature birth  
**Group affiliations:** Parents of Premies - Board Member  
Parent Care  
**Health care facility where child receives majority of care:** Memorial  
Hospital - Nashua, NH  
**Skills and interests:** Parent and family support  
**Experience:** Starting or maintaining support groups

**Martha-Jean and Robert Madison**

RFD #1 Box 169A  
Pittsfield, NH 03263  
603 942-5540

**Children's disabilities:** Mental retardation; physical handicaps  
Severe cerebral agenesis; severe medical needs  
Cerebral palsy; mental retardation  
Developmental delay; attention deficit  
Emotional disturbance  
Learning disability; hearing impairment  
Splenoctomy

**Group affiliation:** \*New Hampshire Parent Information Center (P.I.C.)

**Health care facilities where children receive majority of care:**

Concord Clinic - Concord, NH; Mary Hitchcock Hospital - Hanover, NH

**Skills and interests:** Coordinating services for children with special needs; workshops for families; public relations

**Experience:** Public speaking; leading training for health providers/teachers; starting or maintaining support groups; working with state health departments

**Profession:** Respite/Specialized Homes Coordinator (Robert)

**R. Carol Wallenstein**

8 Kent Street  
Concord, NH 03301  
603 225-9683

**Child's disability:** Congenital rubella syndrome; deaf-blind

**Group affiliations:** International Association for Education of Deaf-Blind (I.A.E.D.B.)

The Canadian Deaf-Blind and Rubella Association

**Health care facility where child receives majority of care:** Concord Hospital - Concord, NH

**Experience:** Past Board Member, State Parent Information Center, New Hampshire Educational Services for Visually Impaired; North-American Regional Coordinator, I.A.E.D.B.; Past State Parent Representative, New England Regional Center for Deaf-Blind Children; Past State Parent Representative Region I Center for Services to Deaf-Blind Children; promoting legislation; working with state health departments

## NEW JERSEY

**Rona Birnbaum**  
7 Washington Park  
Maplewood, NJ 07040  
201 789-4368  
201 763-1474

**Child's disability:** Spina bifida  
**Group affiliation:** Spina Bifida Association of Metropolitan New Jersey  
**Health care facility where child receives majority of care:** Children's Specialized Hospital - Mountainside, NJ  
**Skills and interests:** Fund raising for orthopedic appliances; support to new parents  
**Experience:** Starting or maintaining support groups  
**Profession:** Sales representative for Merrill Lynch  
**Participation in ACCH Parent Network meetings (years):** 1986

**Diana Cuthbertson**  
630 Fairmont Avenue  
Westfield, NJ 07090  
201 654-4333

**Child's disability:** Visual impairment; learning disabilities; recovered from cancer  
**Group affiliations:** \*Federation for Children with Special Needs, CAPP  
-Project (Collaboration Among Parents and Health Professionals) - Consultant  
National Association for Parents of the Visually Impaired  
Adaptive Environments Center  
**Health care facility where child receives majority of care:** Children's Hospital of Philadelphia - Philadelphia, PA  
**Skills and interests:** Developing evaluation materials for parent training programs; bringing the parent perspective to the health care plan; parent networking; parent/professional collaboration  
**Experience:** Member, American Foundation for the Blind, Early Years Advisory Committee; Board Member, National Association for Parents of the Visually Impaired; Past Chairperson, Massachusetts Developmental Disabilities Council Task Force on Family Support; public speaking; leading training for health providers/teachers; promoting legislation; starting or maintaining support groups; working with state health departments  
**Profession:** MPH; R.N.

**Annette Tocco**  
14 Ohio Terrace  
Medford, NJ 08055  
609 953-0656

**Children's disabilities:** Microcephaly  
Microcephaly

**Skills and interests:** Parent advocacy; parents as case managers

**NEW MEXICO**

**Polly Arango**  
P.O. Box 338  
Algodones, NM 87001  
505 867-3159

**Child's disability:** Cerebral palsy

**Group affiliation:** Parents Reaching Out (PRO) - President

**Health care facility where child receives majority of care:** El Pueblo Health Clinic - Bernalillo, NM

**Skills and interests:** Parent advocacy and organizing; medical, educational, and social issues for children with special needs in the foster care system; writing and editing

**Experience:** Developed legislation that led to Medically Fragile Children's Program; Former Member, Medically Fragile Children's Program Advisory Board; Former Board Member, Carrie Tingley Hospital; Board Member, El Pueblo Health Clinic; writing and editing speeches, fact sheets, brochures, articles; public speaking; leading and planning training for health providers/teachers; promoting legislation; starting or maintaining support groups; working with state health departments

**Profession:** Freelance writer; Consultant to non-profit agencies providing outreach to handicapped children and families

**Loretta A. Armenta**  
6405 Concordia NE  
Albuquerque, NM 87109  
505 881-1111  
505 821-4763

**Child's disability:** Sturge-Weber Syndrome  
**Group affiliation:** Parents Reaching Out (PRO)  
**Skills and interests:** State support for home care for medically fragile children; medical services for minorities and indigent; adolescent issues  
**Experience:** Member, Medically Fragile Children's Program Advisory Board; public speaking; leading training for health providers/teachers; promoting legislation; starting or maintaining support groups; working with state health departments  
**Profession:** Insurance agent  
**Participation in ACCH Parent Network meetings (years):** 1985, 1986

**Patti Bearpaw**  
7008 Aztec N.E.  
Albuquerque, NM 87110  
505 293-5800  
505 884-4198

**Child's disability:** Diaphragmatic hernia; ventilator dependent  
**Group affiliations:** SKIP of New Mexico  
Rainbow House  
**Health care facility where child receives majority of care:** University of New Mexico Hospital - Albuquerque, NM  
**Skills and interests:** State and national legislative issues; family support  
**Experience:** Public speaking; leading training for health providers/teachers; promoting legislation; starting or maintaining support groups; working with state health departments  
**Profession:** Real estate  
**Participation in ACCH Parent Network meetings (years):** 1984

**Patti Ikard**  
1820 Muscatel  
Carlsbad, NM 88220  
505 885-2363

**Child's disability:** Down Syndrome  
**Group affiliations:** Special Kids Project - Director  
Parents Reaching Out (PRO)  
ARC

**Skills and interests:** Training parents and professionals on PL 94-142; lobbyist for parent groups to mandate special education for 0-3  
**Experience:** Co-chair and Parent Advisor, New Mexico Legislative Education Study Committee; Parent Advisor, Handicapped Children's Early Education Plan; Parent Representative, Governor's Committee for Chronically Impaired; Chairperson, Committee on Uninsurables  
**Profession:** Director, Special Kids Project; Field Site Coordinator, Family Support Project for PRO

**Dale Lautenschlager**  
566 Todd Loop  
Los Alamos, NM 87544  
505 672-9726

**Child's disability:** Multiple impairments  
**Group affiliation:** Parents Reaching Out (PRO) - Board Member  
**Skills and interests:** Parent-to-parent support  
**Experience:** Public speaking; leading training for health providers/teachers; promoting legislation; starting or maintaining support groups; working with state health departments  
**Participation in ACCH Parent Network meetings (years):** 1985

**Marion Schroeder**  
7810 Charger Trail, N.E.  
Albuquerque, NM 87109  
505 821-5435

**Child's disability:** Cystic fibrosis  
**Group affiliation:** Cystic Fibrosis Foundation  
**Health care facility where child receives majority of care:** University of New Mexico Hospital - Albuquerque, NM  
**Skills and interests:** Parent-to-parent support; insurance for high risk individuals; transitional care for children with chronic illness  
**Experience:** Public speaking; leading training for health providers/teachers; promoting legislation; starting or maintaining support groups; working with state health departments  
**Participation in ACCE Parent Network meetings (years):** 1986

**Cathie Thomas**

7418 Palm Lane, S.W.  
Albuquerque, NM 87105  
505 841-6143  
505 831-2247

**Children's disabilities:** Bronchopulmonary dysplasia; Down Syndrome  
Bronchopulmonary dysplasia; hydrocephalus

**Group affiliation:** Parents Reaching Out (PRO) - Vice President

**Health care facilities where children receive majority of care:**  
University of New Mexico Hospital - Albuquerque, NM; Presbyterian  
Hospital - Albuquerque, NM

**Skills and interests:** Support for families with medically fragile  
children

**Experience:** Member, Medically Fragile Children's Program Task Force;  
public speaking; leading training for health providers/teachers;  
promoting legislation; starting or maintaining support groups; working  
with state health departments

**Profession:** Social worker, Human Service Division

**Participation in ACCH Parent Network meetings (years):** 1986

**Tammy West**

7303 Montgomery, N.E. H-190  
Albuquerque, NM 87109  
505 881-8835

**Child's disability:** Medically fragile; profoundly handicapped  
(deceased)

**Group affiliation:** Parents Reaching Out (PRO)

**Skills and interests:** Support for families with medically fragile  
children; promoting legislation to support families and children

**Experience:** Chairperson, Medically Fragile Children's Program Advisory  
Board; Member, New Mexico Developmental Disabilities Planning Council;  
public speaking; leading training for health providers/teachers;  
promoting legislation; working with state health departments

**Profession:** Parent Advisor, Developmental Disabilities Division,  
University of New Mexico

**Participation in ACCH Parent Network meetings (years):** 1984, 1985

NEW YORK

**Dawne Flammger**

14 Leawood Drive  
Tonawanda, NY 14150  
716 633-5333  
716 695-8007

**Child's disability:** Diaphragmatic hernia; mild cerebral palsy  
**Group affiliation:** AGAPE Parent Fellowship - Director  
**Health care facility where child receives majority of care:** Children's Hospital - Buffalo, NY  
**Skills and interests:** Parent-to-parent support; training for medical students; developing respite care facility; systems for telephone support  
**Experience:** Public speaking; leading training for health providers/teachers; promoting legislation; starting or maintaining support groups  
**Profession:** Travel agency manager

**Margaret Mikol**

500 East 83rd Street  
Suite 113  
New York, NY 10028  
212 734-0728  
212 628-5994

**Child's disability:** Ventilator dependent (deceased)  
**Group affiliation:** SKIP of New York - Executive Director  
**Health care facility where child received majority of care:** New York Hospital - New York, NY  
**Skills and interests:** Family advocacy  
**Experience:** Public speaking; leading training for health providers/teachers; promoting legislation; starting or maintaining support groups; working with state health departments  
**Profession:** Executive Director, SKIP of New York

## NORTH CAROLINA

**Frank Graziadei**  
6915 Dulverton Drive  
Charlotte, NC 28226  
704 595-6123  
704 365-1219

**Children's disabilities:** Duchenne's Muscular Dystrophy  
Learning disability

**Group affiliation:** Exceptional Children's Advocacy Council -  
Chairperson

**Health care facility where children receive majority of care:**  
Charlotte Rehabilitation Center - Charlotte, NC

**Skills and interests:** Educating professionals who work with families  
with exceptional children; parent/professional collaboration

**Experience:** Past President, Muscular Dystrophy Association, South  
Fiedmont Chapter; public speaking; leading training for health  
providers/teachers; promoting legislation; starting or maintaining  
support groups; working with state health departments

**Profession:** Financial planner for IBM

**Joanne Mackey**  
213 Haverhill Drive  
Fayetteville, NC 28304  
919 486-1605  
919 868-1408

**Child's disability:** Spina bifida and hydrocephalus

**Group affiliations:** Parents Helping Parents - Coordinator  
Spina Bifida Association of South Central NC -  
Past President

**Skills and Interests:** Parent-to-parent support; legislative action for  
children with chronic illness; developing "Whole Parents Catalog" for  
parents of children with special needs

**Experience:** Grant and Legislative Liaison, Spina Bifida Association of  
South Central North Carolina; public speaking; leading training for  
health providers/teachers; promoting legislation; starting or  
maintaining support groups; working with state health departments

**Profession:** R.N.

**Participation in ACCH Parent Network meetings (years):** 1986

**Janet Sonnenberg**  
162 Virginia Road  
Box 58  
Montreat, NC 28757  
704 669-5599

**Child's disability:** Burns  
**Health care facility where child receives majority of care:** Shriners  
Burn Institute - Boston, MA  
**Skills and interests:** Family-centered care policies/programs in  
hospitals; writing and public awareness about children with burns  
**Experience:** Member, Family-Centered Care Committee, Shriners Burn  
Institute; public speaking  
**Profession:** R.N.  
**Participation in ACCH Parent Network meetings (years):** 1985, 1986

**Beth Stewart**  
Route 1, Box 412  
Haw River, NC 27258  
919 684-3401  
919 578-5038

**Child's disability:** Cancer (rhabdomyosarcoma)  
**Group affiliations:** Parents and Professionals Together - Program  
Director, Duke University Medical Center  
Parents Reach Out - Board Member  
**Skills and interests:** Parent support; pediatric hospice care; writing  
handbook for parents of children with cancer; statewide parent  
networking; sibling support and education for siblings  
**Experience:** Public speaking; starting or maintaining support groups  
**Profession:** R.N.; Parent Consultant/Nurse Clinician, Pediatric  
Hematology/Oncology, Duke University Medical Center  
**Participation in ACCH Parent Network meetings (years):** 1986

## OHIO

**Pat Hackett-Waters**

621 Mehring Way, Apt. 801  
Cincinnati, OH 45202  
513 541-3663  
513 241-4952

**Child's disability:** Spinal Muscular Atrophy  
**Group affiliation:** Families of Spinal Muscular Atrophy - Education Consultant

**Skills and interests:** Educational consultant; parent-to-parent support; training parents as care managers

**Experience:** Public speaking; leading training for health providers/teachers; promoting legislation; starting or maintaining support groups;

**Profession:** M.Ed.; Teacher

**Participation in ACCH Parent Network meetings (years):** 1983, 1984, 1985, 1986

**George and Bobbie Sich**

4815 Carlow Circle  
Middletown, OH 43042  
513 423-0243

**Child's disability:** Spina bifida

**Group affiliations:** Spina Bifida Association of Cincinnati  
Ohio Spina Bifida Coalition - Secretary  
Middletown City Schools, Parent Advisory Council  
for Special Education  
Spina Bifida Association of America

**Health care facility where child receives majority of care:** University of Cincinnati, Center for Developmental Disabilities - Cincinnati, OH

**Skills and interests:** Educational issues for children with special needs; parent support and advocacy

**Experience:** Vice President, Bylaws Chairperson and Strategic Planning Chairperson, Spina Bifida Association of America; public speaking; leading training for health providers/teachers; promoting legislation; starting or maintaining support groups; working with state health departments

**Profession:** Speech pathologist (Bobbie); Engineer (George)

**Ann Toomey**  
2169 Glenbury Street  
Lakewood, OH 44107  
216 221-0926

**Children's disabilities:** Spina bifida  
Spina bifida

**Group affiliation:** Greater Cleveland Spina Bifida Association

**Health care facility where children receive majority of care:**  
Cleveland Clinic - Cleveland, OH

**Skills and interests:** Parent-to-parent support; outreach to families;  
parent/professional collaboration

**Experience:** Public speaking; leading training for health  
providers/teachers; promoting legislation; starting or maintaining  
support groups; working with state health departments

### OREGON

**Marie Deatherage-Newson**  
2432 S.E. Madison  
Portland, OR 97214  
503 234-2644

**Child's disability:** Spina bifida and hydrocephalus

**Group affiliation:** Columbia River Spina Bifida Association

**Skills and interests:** Newsletter editor; parent-to-parent support

**Experience:** Public speaking; leading training for health  
providers/teachers; starting or maintaining support groups; working  
with state health departments

**Profession:** Regional Consultant, \*COPE (Coalition in Oregon for Parent  
Education)

**Elsie Edge**

9915 S.W. Killarney Lane  
Tualatin, OR 97062  
503 692-6157

**Child's disability:** Encephalocele; hydrocephalus; developmental delay

**Group affiliations:** Pilot Parents - Member, Steering Committee  
Washington County Early Intervention Advisory  
Group - Chairperson  
Oregon State Parents' Council for Early  
Intervention

**Health care facility where child receives majority of care:** Emanuel  
Hospital - Portland, OR

**Skills and interests:** Parent support and advocacy; networking at  
county and state level for continuum of education services; early  
intervention

**Experience:** Parent Representative for Oregon, Zero to Three Project;  
public speaking; participated in training for health  
providers/teachers; starting or maintaining support group

**Pam Kourafas**

2612 S.W. Tegart  
Gresham, OR 97030  
503 234-9991

**Child's disability:** Tuberous sclerosis

**Group affiliation:** Association for Severely Other Health Impaired  
(ASOHI) - Treasurer

**Skills and interests:** Increasing educational options; issues and  
services for children with chronic illness; parent/professional  
partnerships

**Experience:** Leading training for health providers/teachers; promoting  
legislation; starting or maintaining support groups; working with state  
health departments

**Participation in ACCH Parent Network meetings (years):** 1986

**Frank Quan**  
12030 SE Woodward Place  
Portland, OR 97266  
503 251-9464

**Child's disability:** Quadriplegia with medical impairments  
**Group affiliation:** Association for Severely Other Health Impaired  
(ASOHI) - Secretary  
**Health care facility where child receives majority of care:** Oregon  
Health Sciences University - Portland, OR  
**Skills and interests:** Parent advocacy at the state level  
**Experience:** Promoting legislation; starting or maintaining support  
groups  
**Profession:** Accounting, data processing

**Niki Smith**  
840 Hood N.E.  
Salem, OR 97303  
503 581-5034

**Child's disability:** Down Syndrome  
**Group affiliations:** \*COPE (Coalition in Oregon for Parent Education)  
-Regional Consultant  
ARC - Chair, Education Committee for Policy Review  
**Health care facility where child receives majority of care:** Oregon  
Health Sciences University Hospital - Portland, OR  
**Skills and interests:** Family support and advocacy; information  
"broker" on education issues; workshops for parents and professionals  
**Experience:** Advocate, Oregon State Early Intervention Council; Member,  
State Training Center Review Board; public speaking; leading training  
for health providers/teachers; promoting legislation; starting or  
maintaining support groups  
**Profession:** Regional consultant, \*COPE

**Becky Venice**  
138 North H Street  
Cottage Grove, OR 97424  
503 942-4269

**Child's disability:** Down Syndrome  
**Group affiliations:** \*COPE (Coalition in Oregon for Parent Education) -  
-Regional Consultant  
ARC  
National Down Syndrome Congress  
**Skills and interests:** Development of independent living opportunities  
**Experience:** Public speaking; leading training for health  
providers/teachers; promoting legislation; starting or maintaining  
support groups  
**Profession:** Regional consultant, \*COPE  
**Participation in ACCH Parent Network meetings (years):** 1986

**PENNSYLVANIA**

**Kathleen M. Cleaver**

708 Summit Avenue  
Philadelphia, PA 19128  
215 482-1207

**Child's disability:** Cerebral palsy; mental retardation  
**Group affiliation:** Parents Exchange  
**Health care facility where child receives majority of care:** Children's Rehabilitation Hospital - Philadelphia, PA  
**Skills and interests:** Develop and expand information and referral systems for families in Pennsylvania  
**Experience:** Starting or maintaining support groups  
**Participation in ACCH Parent Network meetings (years):** 1986

**Laura Jenewicz**

2583 Balwynne Park Road  
Philadelphia, PA 19131  
215 877-5111

**Child's disability:** Cerebral palsy  
**Group affiliation:** Parents Exchange  
**Health care facility where child receives majority of care:** Children's Rehabilitation Hospital - Philadelphia, PA  
**Skills and interests:** Co-founder family information and referral system; expand information services for families in Pennsylvania  
**Experience:** Starting or maintaining support groups; working with state health departments  
**Participation in ACCH Parent Network meetings (years):** 1986

**Carolyn F. Morris**

7906 St. Martins Lane  
Philadelphia PA 19118  
215 247-9431

**Child's disability:** Cerebral palsy  
**Group affiliation:** United Cerebral Palsy Association  
**Health care facilities where child receives majority of care:** Kennedy Institute - Baltimore, MD; Children's Rehabilitation Hospital - Philadelphia, PA  
**Skills and interests:** Parent support at local level  
**Experience:** Promoting legislation

**RHODE ISLAND**

**Joy Benson**

10 C Sandy Point Farms  
Portsmouth, RI 02871  
401 277-5497  
401 847-7157

**Child's disability:** Spina bifida

**Health care facilities where child receives majority of care:** St. Joseph's Hospital - Providence, RI; Children's Hospital - Boston, MA

**Skills and interests:** Parent-to-parent support

**Experience:** Public speaking; leading training for health providers/teachers; starting or maintaining support groups;

**Profession:** Parent Consultant, Pediatric Oncology Service, Rhode Island Hospital

**Participation in ACCH Parent Network meetings (years):** 1983, 1984

**Helena G. Richards**

34 Gentian Drive  
South Kingston, RI 02879  
401 277-5497  
401 783-9293

**Child's disability:** Leukemia (deceased)

**Group affiliation:** Candlelighters Childhood Cancer Foundation

**Health care facility where child received majority of care:** Rhode Island Hospital - Providence, RI

**Skills and interests:** Parent-to-parent support

**Experience:** Public speaking; leading training for health providers/teachers; starting or maintaining support groups; working with state health departments

**Profession:** Parent Consultant, Pediatric Oncology Service, Rhode Island Hospital

**Participation in ACCH Parent Network meetings (years):** 1985, 1986

## SOUTH DAKOTA

**Dawn Kellogg**  
1714 38th Street  
Rapid City, SD 57702  
605 341-1955

**Child's Disability:** Static encephalopathy; microcephaly; severe developmental delay

**Group affiliations:** Positive Parent Network  
ARC

**Health care facility where child receives majority of care:** Rapid City Regional Hospital - Rapid City, SD

**Skills and interests:** Expanding parent-to-parent outreach throughout state; develop Parent Advisory Board at hospital

**Experience:** Parent Representative, State Health Advisory Board to Maternal and Child Health; Parent Representative, State Department of Special Education Interagency Council for developing and implementing guidelines for P.L. 99-457; public speaking; leading training for health providers/teachers; starting or maintaining support groups; working with state health departments

**Profession:** R.N.

**Participation in ACCH Parent Network meetings (years):** 1986

## TENNESSEE

**Nancy Dean**  
1305 Candlewick  
Knoxville, TN 37922  
615 690-6520

**Child's disability:** Blind

**Health care facility where child receives majority of care:** East Tennessee Children's Rehabilitation Center - Knoxville, TN

**Skills and interests:** Parent-to-parent support; developed Mother's Day Out Program; developing sibling groups

**Experience:** Leading training for health providers/teachers; starting or maintaining support groups

**Participation in ACCH Parent Network meetings (years):** 1986

**Mary Goldsack**  
415 Wrather  
Murreesboro, TN 37130  
615 893-1449

**Child's disability:** Cancer (rhabdomy sarcoma)  
**Group affiliation:** Parents of Special Children  
**Health care facility where child receives majority of care:** Vanderbilt University Hospital - Nashville, TN  
**Skills and interests:** Parent-to-parent support program facilitator; hospital visitation policies  
**Experience:** Public speaking; starting or maintaining support groups  
**Profession:** R.N.; Prenatal class instructor  
**Participation in ACCH Parent Network meetings (years):** 1983, 1985

**Kathleen Rutherford**  
301 Hillcrest  
Clinton, TN 37716  
615 690-8961  
615 457-2793

**Child's disability:** Cerebral palsy; seizures  
**Health care facility where child receives majority of care:** East Tennessee Children's Rehabilitation Center - Knoxville, TN  
**Skills and interests:** Parent-to-parent support; sibling support; parent/professional collaboration; early intervention  
**Experience:** Vice President, POSTOP (Parents Offering Support to Other Parents); Parent Volunteer, Mother's Day Out Program; Parent Counselor, Crippled Children's Services Clinic; Knox County Chairperson, Cerebral Palsy of East Tennessee; Member, East Tennessee Coalition for Young Children; starting or maintaining support groups; working with state health departments  
**Participation in ACCH Parent Network meetings (years):** 1986

**TEXAS**

**Kathy Angel**

5320 Montrose Boulevard  
Houston, TX 77005  
713 528-4528

**Child's disability:** Juvenile rheumatoid arthritis

**Group affiliation:** American Juvenile Arthritis Association -  
President

**Skills and interests:** Developing training programs for parent  
advocacy; organizing national conferences on rheumatoid diseases for  
families and health professionals

**Experience:** Member, Advisory Panel, Regional Pediatric Rheumatology  
Center, Texas Children's Hospital; public speaking; promoting  
legislation; starting or maintaining a parent support group

**Participation in ACCH Parent Network meetings (years):** 1984

**Ellen Day**

6727 Beauford Drive  
Austin, TX 78750  
512 478-6132  
512 346-7449

**Child's disability:** Spina Bifida

**Group affiliations:** Spina Bifida Association of Texas - Executive  
Director  
Coalition of Texans with Disabilities

**Health care facility where child receives majority of care:**

Brackenridge Hospital - Austin, TX

**Skills and interests:** Educational advocacy

**Experience:** Advisory Board, Brackenridge Hospital; Clinic Volunteer,  
Brackenridge Hospital; public speaking; leading training for health  
providers/teachers; promoting legislation; starting or maintaining  
support groups; working with state health departments

**Pat Downey**  
807 Stetters  
Arlington, TX 76017  
817 467-7565

**Child's disability:** I-cell disease (deceased)  
**Health care facility where child received majority of care:** Lutheran  
General - Parkridge, IL  
**Skills and interests:** Freelance writer  
**Experience:** Author of two booklets published by ACCH: Let's Play with  
Our Children and New Directions for Exceptional Parenting; public  
speaking; leading training for health providers/teachers; promoting  
legislation; starting or maintaining support groups  
**Profession:** Purchasing clerk

**Elizabeth Ferguson**  
5331 Spring Meadow  
Dallas, TX 75229  
214 368-3754

**Child's disability:** Juvenile nephronophthisis  
**Group affiliations:** Renal Family Support Team - Chairman  
Children's Kidney Fun Kamp  
**Health care facility where child receives majority of care:** Children's  
Medical Center - Dallas, TX  
**Skills and interests:** Coordinating camp for children with kidney  
problems; parent-to-parent support  
**Experience:** Parent Volunteer, Children's Medical Center  
**Profession:** Choreographer and performing artist  
**Participation in ACCH Parent Network meetings (years):** 1985, 1986

**Vicki Franzen**  
4921 Wildbriar  
Garland, TX 75043  
214 279-0057

**Child's disability:** Leukemia (ALL)  
**Group affiliations:** Children's Cancer Fund - Vice President of Fund  
Raising  
Candlelighters Childhood Cancer Foundation  
**Health care facility where child receives majority of care:** Children's  
Medical Center - Dallas, TX  
**Skills and interests:** Fund raising  
**Experience:** Public speaking  
**Participation in ACCH Parent Network meetings (years):** 1985

**Barbara Ginsburg**  
4034 Leeshire Drive  
Houston, TX 77025  
713 667-7485

**Child's disability:** First Branchial Arch Syndrome; mental retardation  
**Group affiliation:** Confident Parenting Programs - Director  
**Skills and interests:** Parent-to-parent support programs; workshops for families and educators about child development and disabilities; outreach to families  
**Experience:** Conducting parent education programs; working with local Mental Health Mental Retardation Authority; public speaking; leading training for health providers/teachers  
**Profession:** Director, Confident Parenting Programs  
**Participation in ACCH Parent Network meetings (years):** 1986

**Ann and Jerry Hendon**  
503 Hillhurst  
Baytown, TX 77521  
713 656-7336  
713 427-5977

**Child's disability:** Cystic fibrosis (deceased)  
**Group affiliation:** Cystic Fibrosis Parents Support Group  
**Health care facility where child received majority of care:** Texas Children's Hospital - Houston, TX  
**Skills and interests:** Parent-to-parent support; parent/professional collaboration; educational meetings for parents  
**Experience:** Starting or maintaining support groups

**Susan Kalen**  
3424 Marguette  
Dallas, TX 75205  
214 739-3568

**Child's disability:** Asthma  
**Health care facility where child receives majority of care:** Children's Medical Center - Dallas, TX  
**Experience:** Board Member, Women's Auxiliary, Children's Medical Center  
**Participation in ACCH Parent Network meetings (years):** 1985

**Jan Navarre**  
2126 Kowis  
Houston, TX 77093  
713 987-3291

**Child's disability:** Juvenile rheumatoid arthritis  
**Group affiliation:** American Juvenile Arthritis Association  
**Health care facility where child receives majority of care:** Texas Children's Hospital - Houston, TX  
**Skills and interests:** Parent support and education; sports programs for children with disabilities  
**Experience:** Leading training for health providers/teachers; starting or maintaining support groups  
**Profession:** Accountant  
**Participation in ACCH Parent Network meetings (years):** 1984

**Brenda Rapp**  
1906 Clemson  
Richardson, TX 75081  
212 234-8727

**Child's disability:** Cystic fibrosis  
**Group affiliation:** Cystic Fibrosis Foundation  
**Health care facility where child receives majority of care:** Children's Medical Center - Dallas, TX  
**Skills and interests:** Parent and family advocacy; continuing education on cystic fibrosis for patients and families; insurance concerns at state level  
**Experience:** Chairperson, Patient Services Committee; Advisor to Public Policy Committee; Board Member, Cystic Fibrosis Foundation; Committee Member, Cystic Fibrosis Information Time; public speaking; leading training for health providers/teachers; promoting legislation; starting or maintaining support groups; working with state health departments  
**Participation in ACCH Parent Network meetings (years):** 1985, 1986

## UTAH

**Pat Shifflett**  
6393 Silver Bell  
Murray, UT 84107  
801 261-3918

**Child's disability:** Cerebral palsy

**Group affiliations:** Developmental Disabilities Preschool and Early  
Intervention Program  
Legal Coalition of Handicapped Persons

**Health care facility where child receives majority of care:**

Handicapped Children's Services - Salt Lake City, UT

**Skills and interests:** Networking and parent support

**Experience:** Member, State Advisory Board to make policy for the 0-3  
population; public speaking; promoting legislation; starting or  
maintaining support groups; working with state health departments

**Profession:** Nursing student (BSN)

## VERMONT

**Debra R. Asselin**  
Welch Road  
Topsham, VT 05076  
802 439-5282

**Child's disability:** Premature birth, bronchopulmonary dysplasia

**Group affiliation:** Parents of Premies

**Health care facility where child receives majority of care:**

Massachusetts General Hospital - Boston, MA

**Skills and interests:** Parent-to-parent support groups; training and  
support for families

**Experience:** Public speaking; leading training for health  
providers/teachers; starting or maintaining support groups; working  
with state health departments

## VIRGINIA

**Cyndi Cline**  
10913 Belvoir Road  
Chester, VA 23831  
804 748-4881

**Child's disability:** Bronchopulmonary dysplasia; ventilator dependent  
**Group affiliations:** SKIP of Virginia - Director  
American Lung Association of Southside Virginia -  
Board member  
**Health care facility where child receives majority of care:** Medical  
College of Virginia - Richmond, VA  
**Skills and interests:** Parent support; increasing public awareness of  
needs of technology dependent children; promoting legislation for  
medicaid home care waiver system  
**Experience:** Public speaking; promoting legislation; starting or  
maintaining support groups; working with state health departments  
**Profession:** Parent Advisor, Parent-to-Parent; dental assistant  
**Participation in ACCH Parent Network meetings (years):** 1986

**Sue Ferguson**  
505 East Columbia Street  
Falls Church, VA 22046  
703 237-9089

**Child's disability:** Cerebral palsy; seizure disorder  
**Health care facility where child receives majority of care:** Georgetown  
University Hospital - Washington, DC  
**Skills and interests:** Developing case management services for  
families; promoting legislation  
**Experience:** Degrees and experience in special education

**Jane Purdy**  
4615 Gramlee Circle  
Fairfax, VA 22032  
703 978-4111

**Child's disability:** Cerebral palsy; learning disability

**Group affiliations:** Northern Virginia ACLD  
ARC  
Committee for Exceptional Children

**Health care facility where child receives majority of care:** Children's Hospital National Medical Center - Washington, DC

**Skills and interests:** Public speaking and writing; parent-to-parent support; consulting to families of children with special needs

**Experience:** Public speaking; leading training for health providers/teachers; starting or maintaining support groups; working with state health departments

**Profession:** R.N.; Special Needs Family Consultant, U.S. Coast Guard

**Participation in ACCH Parent Network meetings (years):** 1985

**Greg and Lori Weigle**  
451 Orchard Street  
Vienna, VA 22180  
703 281-1211

**Children's disabilities:** Down Syndrome  
Down Syndrome  
Seizure disorder; failure to thrive

**Group affiliations:** Alliance of Genetic Support Groups  
Parents of Down Syndrome Children  
National Down Syndrome Congress

**Health care facilities where children receive majority of care:** Children's Hospital National Medical Center - Washington, DC;  
Fairfax Hospital - Fairfax, VA

**Skills and interests:** Advocacy at the state and national level; assist with foster care, adoptions and parent outreach; professional education

**Experience:** Public speaking; leading training for health providers/teachers; promoting legislation; starting or maintaining support groups; working with state health departments

**Beth Wroblewski**  
6160 Martins Landing Court  
Burke, VA 22015  
703 250-0930

**Child's disability:** Malabsorption; intractable diarrhea; allergic enteropathy  
**Group affiliation:** Parents of Chronically Ill Children - Co-founder  
**Health care facility where child receives majority of care:** Georgetown University Hospital - Washington, DC  
**Skills and interests:** Parent-to-parent support and networking  
**Experience:** Starting or maintaining support groups; working with state health departments  
**Participation in ACCH Parent Network meetings (years):** 1986

### WASHINGTON

**Barbara Bilyeu**  
2603 North Union Avenue  
Tacoma, WA 98407  
206 272-7804  
206 759-7933

**Child's disability:** Sturge-Weber Syndrome  
**Group affiliation:** \*PAVE (Parents Advocating Vocational Education) -  
-Parent Trainer  
Parent to Parent Training Project  
**Skills and interests:** Parent training in PL 94-142; least restrictive environment, normalization, transition  
**Experience:** Past President, Parents Advisory Council, Federal Way Local Education Agency; speaker on educational rights and responsibilities for parents of children with special needs; leading training for health providers/teachers; promoting legislation; starting or maintaining support groups;  
**Profession:** Parent trainer, \*PAVE  
**Participation in ACCH Parent Network meetings (years):** 1986

**Jo Butts**

1010 South I Street  
Tacoma, WA 98405  
206 272-7804  
206 893-2395

**Child's disability:** Cerebral palsy; learning disability  
**Group affiliations:** \*PAVE (Parents Advocating Vocational Education) -  
-Assistant Director  
TAPP (Technical Assistance for Parents Program) -  
Technical Assistance Coordinator

**Health care facility where child receives majority of care:** Good  
Samaritan Children's Therapy Unit - Puyallup, WA

**Skills and interests:** Support for parents; leading training in PL 94-142

**Experience:** Public speaking; leading training for health providers/teachers; starting or maintaining support groups

**Profession:** Assistant Director, \*PAVE

**WEST VIRGINIA**

**Joyce F. Altizer**  
4613 Sixth Avenue  
Vienna, WV 26105  
304 295-5435

**Child's disability:** Multiple congenital disabilities

**Group affiliation:** We've Been There

**Skills and interests:** Parent-to-parent support; wc kshops for health care professionals on need to improve services; early childhood/special education

**Experience:** Serving on State Interagency Committee for Preschoolers with Handicaps; public speaking; leading training for health providers/teachers; promoting legislation; starting or maintaining support groups; working wit. state health departments

**Participation in ACCH Parent Network meetings (years):** 1986

**WISCONSIN**

**Valerie Schreiner**  
203 Brookfield Drive  
Stratford, WI 54484  
715-687-4551

**Child's disability:** Short bowel syndrome

**Group affiliation:** Parent Support Group - Founder

**Health care facility where child receives majority of care:** Marshfield  
Clinic - Marshfield, WI

**Skills and interests:** Parent-to-parent support; working with families  
after hospital discharge

**Experience:** Starting or maintaining parent support group

**Profession:** R.N.

**CANADA**

**ALBERTA**

**Phyllis Kane**

6803 54th Avenue, N.W.  
Calgary, AB T3B 3N4  
403 247-3055

**Children's disabilities:** Asthma; allergy  
Asthma; allergy  
Asthma; allergy; spondylolisthesis

**Group affiliations:** Children's Hospital Community Advisory Committee-  
Chairperson  
Allergy/Asthma Association of Calgary - Founder

**Health care facility where children receive majority of care:** Alberta  
Children's Hospital - Calgary, Alberta

**Skills and interests:** Respite care for medically fragile; early  
intervention resources for handicapped children; care by parent units  
in hospitals

**Experience:** Chairperson, Alberta Children's Hospital Community  
Advisory Committee; public speaking; conducting seminars for health  
providers/teachers; promoting legislation; starting and maintaining  
support groups; working with provincial health departments

**Participation in ACCH Parent Network meetings (years):** 1986

**Nancy Watson**

Alberta Children's Hospital  
Parent Services  
1820 Richmond Road, S.W.  
Calgary, AB T2T 5C7  
403 229-7281  
403 243-2275

**Child's disability:** Cerebral palsy

**Group affiliation:** Cerebral Palsy Association of Calgary

**Health care facility where child receives majority of care:** Alberta  
Children's Hospital - Calgary, Alberta

**Skills and interests:** Parent-to-parent support; parent/professional  
collaboration; improve continuity of care for families

**Experience:** Representative, Community Advisory Committee, Alberta  
Children's Hospital

**Profession:** Parent services in outpatient clinics, Alberta Children's  
Hospital

**Participation in ACCH Parent Network meetings (years):** 1986

**BRITISH COLUMBIA**

**Valerie L. Brotherton**

P.O. Box 2195  
Sechelt BC V0N 3A0  
604 885-7033  
604 885-2910

**Child's disability:** Kasabach-Merritt Syndrome; cavernous hemangioma  
(deceased)

**Group affiliation:** Network for Kasabach-Merritt Syndrome - Founder

**Health care facility where child received majority of care:** Children's  
Hospital - Vancouver, British Columbia

**Skills and interests:** Parent-to-parent support; establishing parent  
network

**Experience:** Public speaking; starting or maintaining support groups

**Sandra Williams**

1790 Kilpatrick Avenue  
Courtenay, BC V9N 2Y6  
604 338-8879

**Child's disability:** Congenital heart disease

**Group affiliation:** Y.A.N.A. (You Are Not Alone) - President  
Comox Valley Charitable Bingo Association - Board  
Member

**Health care facility where child receives majority of care:** Children's  
Hospital - Vancouver, British Columbia

**Skills and interests:** Providing funding for families leaving Comox  
Valley for medical care; psychosocial effects of hospitalization on  
families; networking with local hospitals; fundraising

**Experience:** Public speaking; leading training for health  
providers/teachers; starting or maintaining support groups; working  
with provincial health departments

**Profession:** Sales clerk

## NOVA SCOTIA

### **Scott Dickson**

300 Micmac Boulevard #318  
Dartmouth, NS B3A 4L6  
902 466-3332

**Child's disability:** Leukemia

**Group affiliation:** Maritime Candlelighters Childhood Cancer Foundation  
- President

**Health care facility where child receives majority of care:** Izaak Walton Killam Hospital for Children - Halifax, Nova Scotia

**Skills and interests:** Parent support; fundraising, planning family activities and monthly meetings

**Experience:** Public speaking; starting or maintaining support groups

**Profession:** Graphic designer

### **Carol Young**

1191 Dalmousie Street  
Halifax NS B3H 3W5  
902 422-9452

**Child's disability:** Renal transplant; blind

**Group affiliation:** Canadian National Institute for the Blind (CNIB)  
Ronald McDonald House - Board Member

**Health care facility where child receives majority of care:** Izaak Walton Killam Hospital for Children - Halifax, Nova Scotia

**Skills and interests:** Improve hospital services to meet the needs of children and families; parent support

**Experience:** Member, Board of Governors, Izaak Walton Killam Hospital for Children; Board Member and Volunteer, Ronald McDonald House; public speaking; starting or maintaining support groups

**Participation in ACCH Parent Network meetings (years):** 1986

## **ONTARIO**

### **Kathleen Jordan**

5 Holgate Court  
Kanata, ONT K2K 1B4  
613 592-2678

**Child's disability:** Cerebral palsy; visual impairment; seizure disorder

**Group affiliations:** Ottawa Crippled Children's Parent Group  
Special Educational Advisory Committee, Carlton  
Roman Catholic School Board  
Easter Seals Society - Parent Delegate

**Health care facilities where child receives majority of care:**

Children's Hospital of Eastern Ontario (CHEO) - Ottawa, Ontario; Ottawa  
Children's Treatment Center - Ottawa, Ontario

**Skills and interests:** Outreach to families with special needs  
children; networking with parents across the province; advocate for  
improved educational programs and services for exceptional children

**Experience:** Board Member, Views for the Visually Impaired; Member,  
Participating Families, Ontario Federation for the Cerebral Palsied;  
Consumer and Child Advocate, Provincial Ministry of Health Advisory  
Committee to the Minister on Assistive Devices; Member, Advisory  
Committee, Canadian Diabetic Association; public speaking; leading  
training for health providers/teachers; starting or maintaining support  
groups; working with provincial health departments

**Profession:** Member, Federal Human Rights Tribunal Panel; educator

### **Elaine Orrbine**

155 Owl Drive  
Ottawa, ONT K1V 9J5  
613 737-2572  
613 526-4242

**Child's disability:** Nephrotic Syndrome

**Group affiliation:** Kidney Foundation of Canada

**Health care facility where child receives majority of care:** Children's  
Hospital of Eastern Ontario - Ottawa, Ontario

**Skills and interests:** Author of handbook for parents of children with  
nephrotic syndrome - Childhood Nephrotic Syndrome, You and Your Child;  
working on handbook for parents on end-stage renal disease

**Experience:** Public speaking; starting or maintaining support groups

**Profession:** Coordinator, Canadian Pediatric Kidney Disease Reference  
Center

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**Association  
for the  
Care of  
Children's Health**

Humanizing  
Health Care for  
Children  
and Their Families

3615 Wisconsin Avenue, N.W.  
Washington, D C 20016  
(202) 244-1801

**PARENT RESOURCE DIRECTORY INFORMATION FORM**  
**FOR 2ND EDITION**

Please complete this form with any changes in your entry in this directory or pass on to a parent for the next edition of the directory to be published in the summer of 1987.

**PLEASE PRINT OR TYPE.**

1. Name \_\_\_\_\_  
Address \_\_\_\_\_  
City \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_  
Phone (day) (\_\_\_\_) \_\_\_\_\_ (night) (\_\_\_\_) \_\_\_\_\_

2. Child's disability \_\_\_\_\_  
(Please indicate if more than one child has a disability and the disability for each child.)  
\_\_\_\_\_  
\_\_\_\_\_

3. Name of health care facility where child receives majority of care \_\_\_\_\_  
Address \_\_\_\_\_  
City \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_  
Any affiliation with this health facility beyond your role as a parent? Yes \_\_\_\_\_ No \_\_\_\_\_  
If yes, please specify your role \_\_\_\_\_  
\_\_\_\_\_

4. Are you affiliated with any groups or organizations (i.e., disease specific organizations, parent support group)? List as many as you want, including your title and position.

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5. What are your skills, interests or current activities as related to improving child health care or education services?

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6. Do you have experience in any of the following areas?

Public speaking? Yes \_\_\_ No \_\_\_

Conducting training sessions for health care providers or teachers?

Yes \_\_\_ No \_\_\_

Promoting legislation? Yes \_\_\_ No \_\_\_

Starting or maintaining a parent/family support group?

Yes \_\_\_ No \_\_\_

7. What is your profession? \_\_\_\_\_

Are you currently employed? Yes \_\_\_ No \_\_\_

If yes, in what capacity and where? \_\_\_\_\_

---

8. Do you have any affiliation with a federally funded Parent Training and Information Center?

Yes \_\_\_\_\_ No \_\_\_\_\_

If yes, which one and where? \_\_\_\_\_  
\_\_\_\_\_

9. Please describe your involvement with your state's health department.

\_\_\_\_\_ Have you had any involvement with state health agencies? In what way? \_\_\_\_\_  
\_\_\_\_\_

\_\_\_\_\_ Have you worked closely with your state health department? In what way? \_\_\_\_\_  
\_\_\_\_\_

\_\_\_\_\_ Does your child receive health care services from a state health department?

Please describe. \_\_\_\_\_  
\_\_\_\_\_

10. Have any of your children ever been involved with Head Start? Yes \_\_\_\_\_ No \_\_\_\_\_

If yes, what year? \_\_\_\_\_ Where? \_\_\_\_\_

11. Have you ever attended any ACCH Parent Network meetings?

\_\_\_\_\_ 1983 - Chicago

\_\_\_\_\_ 1984 - Houston

\_\_\_\_\_ 1985 - Boston

\_\_\_\_\_ 1986 - San Francisco

\_\_\_\_\_ 1987 - Halifax

12. Below is a list of community services and resources that can be supportive of families caring for children with special needs. Please indicate which services have been of assistance to you.

- \_\_\_ Babysitting services
  - \_\_\_ Camps
  - \_\_\_ Day care program
  - \_\_\_ Early intervention program
  - \_\_\_ Equipment loan or exchange program
  - \_\_\_ Family resource library
  - \_\_\_ Financial assistance for supportive services  
(not for direct health care)
  - \_\_\_ Foster grandparent program or similar  
volunteer program
  - \_\_\_ Home tutoring program
  - \_\_\_ Hospice
  - \_\_\_ In-home nursing care
  - \_\_\_ Lekotek or toy lending library
  - \_\_\_ Parent information center
  - \_\_\_ Parent-to-parent support
  - \_\_\_ Respite care
  - \_\_\_ Sibling support program
  - \_\_\_ Transportation assistance
  - \_\_\_ Other \_\_\_\_\_
- 
- 

Please return to ACCH by June 15, 1987.



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**PARENT RESOURCE DIRECTORY EVALUATION FORM**

1. In what ways have you used, or might you use, this directory?

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2. What other kinds of information would you like to see included in this directory?

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3. What suggestions do you have for improving the usefulness or format of this directory?

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4. Do you have suggestions for people and/or organizations to receive this directory?

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5. Other comments:

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Please return this form to ACCH.

The Association for the Care of Children's Health (ACCH) is an organization of health care professionals and parents which seeks to foster and promote the psychosocial well-being of children and families in health care settings through education, multidisciplinary interaction, and research. Founded in 1965, ACCH has over 3900 members and 50 regional affiliates which offer local and regional educational programs.

This publication has been developed as part of a project funded by the Division of Maternal and Child Health, HHS. The project's overall purpose is to promote parent/professional collaboration and a family-centered approach to health care for infants, children, and adolescents with a chronic illness or disabling condition.