

Resources for People with Facial Differences

Organizations

AboutFace

AboutFace is an international information and support organization for people with facial differences and their families. Their resources include parent support training, books, videos, and a lending library. (See Appendix D for publications.) AboutFace holds training workshops for people interested in giving school presentations and for those who would like to participate in the support-person visitation program. Other resources include a Cleft Care Kit for parents and professionals, and *Making the Difference*, an orientation package for health-care providers working with a newborn. The National Cleft Palate Association became part of AboutFace in the spring of 1992, and new chapters are being developed throughout North America. Membership, at \$20 per year, includes a bimonthly newsletter. For more information, visit the About Face website at www.aboutface2000.org, or write: Pam Onyx, AboutFace, 1002 Liberty Ln, Warrington, PA 18976;

1-888-486-1209; FAX (215) 491-0603; or in Canada, contact: Betty Bednar, AboutFace, 99 Crown's Ln, Toronto, Ontario, Canada M5R 3P4; or call (416) 597-2229; FAX (416) 944-2488.

American Cleft Palate Craniofacial Association (ACPCA) and Cleft Palate Foundation (CPF)

The ACPCA is a professional organization that includes twenty-seven different disciplines. It offers conferences, medical journals, booklets, and other benefits. Membership is open to qualified individuals involved in treatment or research of cleft lip, cleft palate, and other craniofacial anomalies.

The CPF is the fundraising, educational, and communication component of the ACPCA, providing free information for parents and patients. The CPF has a newsletter (\$7.50 per year) and a CLEFTLINE for parents of newborns (1-800-24-CLEFT). (See Appendix D for publications.) For more information visit www.cleftline.org or write: ACPCA, Nancy Smythe, 104 S. Estes Drive, Suite 204, Chapel Hill, NC 27514; or call (919) 933-9044.

F.A.C.E.

The Friends for Aid, Correction, and Education of Craniofacial Disorders raises money and gives support to people who need reconstructive surgery. For further information, write: Bernice Bergen, PO Box 1424, Sarasota, FL 34230; or call (941) 955-9250.

Face to Face

Formed by Julie Breuninger, a nurse and the mother of a child with Crouzon's Syndrome, this organiza-

tion offers phone consultations for parents, as well as area meetings. For an article about parenting a child with Crouzon's written by Ms. Breuninger, write to: Julie Breuninger, 473 Live Oak Dr, El Cajon, CA 92020.

FACES

The National Association for the Craniofacially Handicapped assists people with craniofacial deformities resulting from birth defects, injuries, or disease. Eligible candidates may apply to this nonprofit organization for financial assistance for nonmedical costs. Support is offered on the basis of financial and medical need for such expenses as travel, lodging, and food when traveling to a craniofacial center for reconstructive surgery. To contact FACES for quarterly newsletter, information about craniofacial disorders, support networks, and/or applications for financial assistance, write: FACES, Box 11082, Chattanooga, TN 37401; or call (423) 266-1632.

Federation for Children with Special Needs

The federation is the main headquarters of a national network of parent information centers. Activities include the CAPP National Resource Center for Children with Special Healthcare Needs. The federation is also a coalition of parent-run organizations for children with a variety of disabilities within Massachusetts. Newsletters, workshops, and information sheets are available by writing: The Federation for Children with Special Needs, 1135 Tremont Street, Suite 420, Boston, MA 02120; or call (617) 236-7210 (voice or TDD); or toll-free 1-800-331-0688.

Forward Face

A parent-to-parent support organization associated with the Institute of Reconstructive Plastic Surgery at New York University Medical Center, Forward Face offers quarterly support meetings open to the public and a newsletter. (See Films and Videos section for Face Facts videotapes.) For more information, write: Patricia Chibbaro, RN, Institute of Reconstructive Surgery, NYU Medical Center, Tisch Hospital, Suite H-169, 560 1st Ave, New York, NY 10016; or call (212) 263-5205.

Foundation for the Faces of Children

Contributions to the foundation support the Craniofacial Center of Children's Hospital Medical Center, Boston, in such areas as clinical, basic, and psychosocial research, postgraduate training in craniofacial surgery, and parent-to-parent support. Contributors receive a newsletter. For parent resource information or to address concerns, write to parent consultant Priscilla Bradway, PO Box 505, Weston, MA 02193; or call (617) 355-6309.

Hemifacial Microsomia Family Support Network: Goldenhar Syndrome

This network offers support and education for parents and families of children born with hemifacial microsomia, including a free printout that describes hemifacial microsomia in lay terms and a newsletter. For more information, you may write to Kayci Rush, a parent of a child with Goldenhar Syndrome, at: 3619 Chicago Avenue, Minneapolis, MN, 55407-2603; or call (612) 823-3529.

Let's Face It

An information and support network for people with facial differences, their families, friends, and professionals, Let's Face It, of Concord, Massachusetts, is the US branch of an international information and support network. Founded by Christine Piff, an Englishwoman who lost her palate and eye to cancer, Let's Face It is independent of any other support network. One of its goals is to let people know they are not alone. The group handles calls from across the country and is able to link people to additional resources and networks. For additional information, write: Let's Face It, P.O. Box 29972, Bellingham, WA 98228-1972; E-mail letsfaceit@faceit.org; or call; (360) 676-7325

National Center for Education in Maternal and Child Health (NCEMCH) and National Maternal and Child Health Clearinghouse (NMCHC)

These sister organizations provide education and information services in maternal and child health. The center, NCEMCH, makes relevant information available through their many publications; a free catalog lists the materials according to specific topics. For more information write: NCEMCH/NMCHC, 2000 15th St, N, Ste 701, Arlington, VA 22201; or call NCEMCH (703) 524-7802; NMCHC (703) 821-8955 ext 254.

National Center for Youth with Disabilities

The center's mission is to improve the health and social functioning of youth with disabilities through technical assistance and consultation, dissemination of information, and increased coordination of services between the health-care system and other

services. The Winter 1992 issue of *Connections*, the center's newsletter, discusses teen weight-control programs, sexual abuse of teens with disabilities, sexuality education program guidelines, and public attitudes toward people with disabilities. The center also offers training materials, new books, information on upcoming conferences, and youth trips. Write: NCYD Connections, University of Minnesota, Box 721 UMHC, Harvard St at E River Rd, Minneapolis, MN 55455; or call 1-800-333-6293 or (612) 625-5000.

National Foundation for Facial Reconstruction

The NFFR sponsors programs of the New York University Medical Center. A library of books and films is available to the public. For complete information, write: Arlyn Gardner, 317 E 34th St, 9th Floor, Room 901, New York, NY 10016; or call (212) 263-6656.

National Information Center for Children and Youth with Disabilities

The center, formerly called the National Information Center for Handicapped Children and Youth, is an information service that assists parents, educators, caregivers, and others in ensuring that all children and youths with disabilities have the opportunity to reach their potential. The center specializes in educational planning, but it also has information on a broad range of topics concerning the needs of children with handicaps. Material is available in large print or braille or can be taped upon request. The free newsletter includes a network exchange that allows people to share their experiences. Write: The National Information Center for Children and Youth with Disabilities, PO Box 1492, Washington, DC 20013; or call (202) 884-8200 (voice or TDD); or toll-free, 1-800-999-5599.

National Information System and Clearinghouse

The Clearinghouse, sponsored by the National Maternal and Child Health Bureau, offers information about children from birth to three years who have disabilities or life-threatening conditions and helps find services for children with special health-care needs or developmental disabilities. Parents and professionals are encouraged to use the center's free hotline and its resources. For more information, write: Center for Developmental Disabilities, University of South Carolina, Benson Bldg, First Floor, Columbia, SC 29208; or call (803) 935-5231; or toll-free 1-800-922-9234.

National Neurofibromatosis Foundation

With support groups located throughout the US, as well as a national newsletter, this foundation supports research and education for parents, patients, and professionals. For more information, write: National Neurofibromatosis Foundation, 95 Pine Street, 16th Floor, New York, NY 10005; or call (212) 344-6633; toll-free 1-800-323-7938.

National Organization for Rare Disorders

NORD is an educational link for organizations and individuals concerned with rare disorders. It tracks legislation, researches diseases, advocates for funding, and awards grant money. *The Orphan Disease Update*, included with the \$25 membership fee, addresses rare disorders and is mailed throughout the world. Annual meeting. For more information, write: NORD, PO Box 8923, New Fairfield, CT 06812-8923; or call (203) 746-6518.

Neurofibromatosis, Inc, Midatlantic Chapter

This organization for families and individuals offers free information about this neurologic genetic disorder, identifies local support groups, provides referrals to local medical resources, encourages research, and educates legislators about NF family needs. Newsletter; conferences. For more information, write: Mary Ann Wilson, 8855 Annapolis Road, Suite 110, Atlanta, MD 20706; or call (301) 577-8984.

Prescription Parents, Inc

This active support network in New England for people with cleft lip and cleft palate offers outreach services to parents of newborns with cleft lip or palate. It also provides legislative advocacy, a newsletter, and social activities. For more information, call (781) 431-1398.

Treacher Collins Foundation

Directed by a social worker and psychologist who have a child with Treacher Collins Syndrome, this foundation's primary goal is to link, through the TC Network, families and individuals affected by TC with each other and with professionals in the field of craniofacial anomalies in order to facilitate the development and sharing of their knowledge and experience. Newsletters; referral lists. For more information, call (802) 649-3050. Website: www.treachercollinsfnd.org; E-mail geomrf@hotmail.com.

***Connecticut Children's Medical Center,
Craniofacial Team***

Serving over six hundred families in the Connecticut area with information, support, and meetings, this support group holds bimonthly conferences. Topics have included "Dealing with the Emotional Aspects of a Craniofacial Disorder" and "The Hows and Whys of Craniofacial Birth Defects." For more information, write: Rita Brzozowski, parent coordinator, Connecticut Children's Medical Center, Craniofacial Team, 282 Washington Street, Hartford, CT 06106; or call (860) 545-9360.

Reading for Parents and Children***Advice to Parents of a Cleft Palate Child*
D. Wicha and M. Folk**

(2nd Ed; 1981), \$12.25. To order, write: Charles C Thomas Publishing, 2600 S First St, Springfield, IL 62704; or call (217) 789-8980.

***Beauty Is the Beast*
Ann Hill Beuf**

Subtitled *Appearance-Impaired Children in America*, this book uses theory and methodology from sociology, anthropology, and psychology, as well as the author's interviews with children and their caretakers. Ms Beuf analyzes both the effects of stigmatization on children and the strategies used to cope. This book can be particularly meaningful for adults with facial disfigurement. 1990, \$14.95. To order, call: University of Pennsylvania Press, (215) 898-6264.

Between Parent & Child***Between Parent & Teenager*****Haim Ginott**

Written by a children's psychiatrist, these books offer a means of building a loving dialogue with children and teenagers. The books have helped bring many parents and children together. Avon Books, 1969. Available through bookstores.

Brothers and Sisters: A Special Part of Exceptional Families**Thomas Powell and Peggy Ogle**

Brothers and sisters of handicapped children are the focus of this book, which addresses such issues as the intensity of sibling relationships, sibling interactions, the factors contributing to a family's adjustment patterns, parental expectations, siblings as teachers, and siblings at school. Information and resources for siblings and parents are listed. 219 pp, paperback. To order, write: Paul H. Brookes Publishing Co, PO Box 10624, Baltimore, MD 21204.

Building the Healing Partnership: Parents, Professionals, and Children with Chronic Illness and Disabilities**Patricia Taner Leff, MD, and Elaine H. Walize**

There are few crises as devastating as finding out that one's child is disabled or seriously ill—one of the themes of this powerful book designed for parents and health professionals. The authors, a psychiatrist and a mother of a special-needs child, cover all the implications of living with mental and physical disabilities. Having a "special" child puts the entire family at risk, and such families must perform extraordinary tasks day after day. The authors pull no punches; the talk is frank, alternately depressing and uplifting. Dozens of entries from parents and health-care workers aim to educate, invite change, and stimulate personal growth. A list of parent resources and a glossary are includ-

ed. This book is excellent for parents, doctors, nurses, therapists, and teachers. Public and school libraries should consider ordering. (Book review by Linda Beck, Indian Valley Public Library, Telford, PA [*Library Journal*]). 1992, paperback, \$24.95. To order, write: Brookline Books, Box 381047, Cambridge, MA 02238; or call (617) 868-0360 or (800) 666-2665.

A Button in Her Ear

Ada Litchfield

This book for children (ages 6–9) addresses the experiences of hearing-disabled children through the story of a girl with a hearing aid. To order, write: Albert Whitman Co, 6340 Oakton St, Morton Grove, IL 60053-2723; or call 1-800-255-7675.

How Different Is Anthony?

Joanne Green

Anthony was born with a cleft lip and palate, but does that really make him very different from other kids? This book helps children born with clefts to recognize themselves as the normal healthy kids they are. This is a self-esteem builder, designed to read aloud. Good for children of all ages, particularly those 4–8 years. To order, write: Wide Smiles/Anthony, PO Box 5753, Stockton, CA 95285- 8153.

Koko Bear's Big Earache (Preparing Your Child for Ear Tube Surgery)

V. Lansky

\$5.95. (Bantam Books: Toronto, New York, London)

Meeting the Challenge: A Training Program for Adolescents with Special Needs

Kathleen Kapp-Simon

Adolescents with special needs are the topic of this training manual and accompanying video that focus on the development of interpersonal skills, self-awareness, and coping strategies. The manual and

video provide theory, training strategies, and a curriculum. Featured in the videotape are several adolescents, some of whom have facial disfigurement. The program can be implemented by psychologists, nurses, social workers, child life specialists, or other professionals. Book, \$30.00; book and video, \$125.00; additional books with video, \$25.00. To order, write: Kathleen Kapp-Simon, UIC Craniofacial Center, Box 6998, Chicago, IL 60680; or call (312) 996-7546.

***A Parent-Child Cleft Palate Curriculum:
Developing Speech and Language***

**Bonnie L. Brookshire, MA, Joan I. Lynch EdD,
and Donna R. Fox, PhD**

Three experimental speech-language pathologists help parents to help their child with a cleft palate to speak well. To order, write: CC Publications, Inc, PO Box 23699, Tigard, OR 97223.

A Parent's Guide to Cleft Lip and Palate

K. Muller, C. Starr, and S. Johnson

"Should be required reading for every new parent of a child with a cleft," says one parent. Chapters range from a basic explanation of the current theory of the cause of clefts, to surgical repair and social and psychological development. To order, write: University of Minnesota Press, 2037 University Ave, SE, Minneapolis, MN 55414.

Rosey . . . The Imperfect Angel

Sandra Lee Peckinpah

Rosey is a positive, uplifting tale for all the world's different children, their parents, their brothers and sisters, their classmates and teachers—for anyone who has ever felt a little different. It is a tale told with real love that holds the promise of a happy ending. 1991, 32 pp. Cloth, \$20.00. To order, write: Dasan Productions, 4201 Hunt Club Ln, Westlake Village, CA; or call 1-800-348-4401 or (416) 597-2229. Also available through: AboutFace, 1002 Liberty Ln, War-

rington PA 18976; 1-800-225-FACE or (215) 491-0602; or in Canada: 99 Crown Ln, 3rd Floor, Toronto, ON, Canada MSR 3P4; (416) 944-FACE.

Wide Smiles Newsletter

While its focus is cleft lip and palate, this quarterly newsletter would also be of interest to parents of children with other craniofacial anomalies. Contributing articles and sharing advice are encouraged. Past articles have featured new studies and technologies, success stories, questions from parents, comments from teenagers, and book reviews. Future articles will focus on new feeding devices for children with cleft lip and palate. Subscription cost: \$18.00 per year. For more information, or to subscribe, write: Joanne Green, PO Box 5153, Stockton, CA 95205-0153; or call (209) 942-2812.

Fun and Games

Danny's Song

Going to Sleep

I Am, I Can, I Will

Josephine, the Short-Necked Giraffe

Family Communications, Inc

In these combination books and audiotapes, Fred Rogers talks and sings about individual strengths and weaknesses and encourages children to explore all that they are. Also available are outstanding and reasonably priced videos, games, and toys. Videotapes preview hospital visits, having an operation, and how to deal with anger, rejection, jealousy, and fear, including the fear of death. Helpful to hospital staff, schools, and families, these packages are produced with the sensitive, creative spirit of any Mister Rogers' production. Write for a catalog: Family Communications, Inc, 4802 Fifth Ave, Pittsburgh, PA 15213; or call (412) 687-2990.

Films and Videos

Center for Craniofacial Anomalies

What Is Going to Happen to My Baby?

This tape is an explanation of cleft lip and palate and an overview of the treatment provided by various disciplines at different stages of development. Audience: Parents and all health professionals associated with treatment of cleft lip/palate. Winner of the American Society of Plastic and Reconstructive Surgery Scientific Exhibit Award (15 min).

Feeding Your Special Baby

This tape shows modified feeding techniques for the baby born with cleft lip/palate. Audience: Parents, nurses, medical students, residents, pediatricians, and speech pathologists. Winner of two national awards of outstanding achievement in the use of television for education in the health sciences: Health Science Communications Association; and American Journal of Nursing Companies, Educational Services Division (15 min; also available in Spanish).

Your Baby's Surgery

An explanation of what a cleft is, how it is repaired, and what hospitalization and postoperative care entails for a baby born with a cleft are the main topics of this concise and informative videotape (13 min).

Being Understood

This tape offers an overview of speech therapy for toddlers and older children with cleft palate. Audience: Parents, speech and language professionals, associated health professionals, and students (13 min).

Pharyngeal Flap

In accessible terms, this tape offers an explanation

of speech mechanisms, hypernasal speech, and how pharyngeal flap surgery corrects this problem. Audience: Parents, patients, and all health professionals associated with cleft lip/palate (13 min; also available in Spanish).

SOM: A Silent Disease

This tape explains why children with cleft palate are susceptible to ear disease, offers advice on what can be done to prevent or correct ear disease in its early stages, and describes myringotomy surgery. Audience: Parents, patients, and all health professionals associated with cleft lip/palate (22 min; also available in Spanish).

Put on a Happy Face

Included here are the reasons children with cleft lip and palate need special attention to maintain good dental health, and a program to achieve this goal. Audience: Parents and all health professionals associated with cleft lip/palate (10 min; also available in Spanish).

All of these videotapes are available from the CCA to rent or to purchase. Rental fee is \$30.00 for a 10-day period. Purchase price is \$95.00. (Rental fee is applicable toward purchase price.) Postage and handling fees are added at time of shipment. To order, write: Marcia Aduss, CCA, University of Illinois College of Medicine at Chicago, PO Box 6998, Room 476 CME, M/C 588, Chicago, IL 60680.

Face Facts

Every maternity medical facility should own a copy of Face Facts' excellent 25-minute videos. They are designed for parents and families to use in the first days after the birth of a child with cleft lip and palate, craniosynostosis, hemifacial microsomia, orbital hypertelorism, or Treacher Collins syndrome.

Narrated by Cliff Robertson, each tape includes an overview of the disorders and features in-depth interviews with medical professionals, educators, family members, and patients. An extended segment highlights specific family concerns.

Prices: \$80.00 for a set of five to professionals and nonmembers (or \$20.00 for a single tape); \$60.00 for Forward Face members (or \$15.00 for a single tape). All profits are used to develop future educational materials concerning craniofacial disorders and their treatment. For more information, write: Patricia Chibbaro, RN, Forward Face, Institute of Reconstructive Plastic Surgery, NYU Medical Center, 560 1st Ave, New York, NY 10016; or call (212) 263-5205.

Cleft Lip and Palate—Feeding the Newborn
Heartstar Productions, Ltd

Developed in 1992 by the Hospital for Sick Children's cleft lip and palate program, this videotape presents the appropriate methods to feed an infant with a cleft lip and/or palate (18 min). The tape sells for \$95.00, but it is possible to preview the video at a cost of \$10.00 (applicable toward the purchase price). For further information, or to order, contact: Sylvia Schippke, Coordinator, Cleft Lip and Palate Program, Hospital for Sick Children, 555 University Ave, Toronto, Ontario, Canada, M5G 1X8; or call (416) 813-7490.

Feeding Aids

To order cleft palate bottles, contact: Mead Johnson Consumer Affairs, (812) 429-5000. For cleft palate NUK nipples, contact: Gerber Consumer Information Service: 1-800-4-GERBER.