

Cleft Palate Parent Groups

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A number of professionals from various disciplines have emphasized the importance of parent counseling and guidance in cleft palate habilitation. For example, Bleiberg and Leubling (4) state "We believe that with understanding comes confidence and that, if the general problems and procedures of cleft palate habilitation are better understood, much parental anxiety and concern may be alleviated; we also believe that informed parents are better able to fulfill their roles and responsibilities as members of the habilitation team." Several topics related to parent counseling and guidance have been discussed in the literature; these include attitudes and adjustment (4, 7, 12, 13, 19, 24), immediate concerns (4, 7, 17), learning about the defect (7, 17), nature of cleft lip and palate (5, 8, 9, 23), parental responsibility in cleft palate habilitation (4, 23), parent child relationships (4, 18), physical handicaps (24), preoperative counseling (8, 10), publications for parents (4, 8, 26, 27), socioeconomic differences (7), and speech-language development and training (5, 9, 16, 19, 23). To date, groups for parents of cleft lip and palate children have not been studied. Thus, the need for such study is indicated.

The value of parent groups has been emphasized by Apgar (1) who quoted a social worker at Washington University Medical Center as saying . . . "although professional people like to think they are the most help to those in distress; I really don't know anyone who can be as helpful to a parent as another parent who either is or has been in the same situation." Moreover, Apgar indicates that professionals can guide parents but increasingly more parents are turning to each other for support. This trend has also been reported elsewhere (3, 11, 25). A 1972 (15) report on the state wide conference of California Cleft Guilds describes the role of parent groups in cleft palate habilitation.

Parent groups may be an effective way to solve in part some of the problems of parents as reported by Bleiberg and Leubling (4). Their survey indicated that most of the difficulties encountered by parents of cleft palate children were related to three primary factors: (a) inadequate parental understanding of the problems and procedures of cleft palate habilitation; (b) emotional factors such as anxiety, hostility, am-

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bivalence, guilt, and bewilderment; and (c) conflicting demands arising from such things as the care required by other children in the family, illness of other family members, and clinic hours occurring during the work day and school.

The survey reported here resulted from an interest in cleft palate parent groups. It was obvious that there was insufficient information about the availability and activities of these groups. An announcement requesting assistance in locating cleft palate parent groups appeared in the January, 1972 issue of the Cleft Palate Journal. Twenty groups were located (Table 1); some through the announcement and others by parent groups.

Procedure

In 1972 and 1973, questionnaires were sent to the twenty parent groups. Returns were received from fifteen, or 75 percent. Since a 75 percent return is relatively high for this type of questionnaire, it appears that an adequate sample was obtained. The questionnaire included requests for information about group identification, membership meetings, finance, goals, and services. The majority of the 64 questions required yes-no or descriptive answers.

Discussion

GROUP IDENTIFICATION. Table 1 shows the names and addresses of the groups, their executive officers, dates of initiation, and number of members. The oldest groups, which were organized in 1962 and 1963, also have the largest number of members, 225 each. Similarly, the youngest groups are also the smallest, established in late 1972 and 1973. The combined number of members for all groups is over 1,344. The majority of members are parents of cleft palate children, but some members are relatives or friends, cleft palate adults, or professionals. Prospective members are located in a variety of ways: "word of mouth," newspaper articles, radio announcements, distribution of literature for parents of cleft palate children, and referrals from agencies (hospitals, crippled children's services, public health departments, cleft palate teams) and individuals (plastic surgeons, dentists, nurses, pediatricians, speech therapists, other parents).

These parent groups were organized primarily to promote (a) parent education and counseling, (b) public education, and (c) cleft palate rehabilitation. The following is a representative list of reasons given for organizing parent groups:

1. "as an outgrowth of a small group of concerned parents wanting to learn more about cleft palate and to be able to support one another; to provide financial aid to the university cleft palate team."
2. "to bring parents of cleft children together to share joys and problems of these children and to inform the community about cleft lip and palate."

TABLE 1. Cleft palate parent groups.

<i>state</i>	<i>group name and address</i>	<i>executive officer(s)</i>	<i>date initiated</i>	<i>no. of members</i>
Arizona	Cleft Parent Group, Inc. 4119 East Beryl Lane Phoenix, Arizona 85028	Mrs. Babs Furst	N.g.*	N.g.*
California	Orange County Cleft Parent Guild 7948 Begonia Circle Buena Park, California 90620	Mr. & Mrs. William Helfrich	N.g.	N.g.
	Cleft Palate Parent Guild 480 South Indiana Hill Blvd. Claremont, California 91711	Mr. & Mrs. John Mizerak	1967	60
	Cleft Parent Group, Inc. 560 Alhambra Street Crockett, California 94525	Mr. & Mrs. Norman Sanders	1973	50
	Cleft Parent Guild of Los Angeles County % Crippled Children's Society 7120 Franklin Ave., Los Angeles, California 90016	Mr. & Mrs. Patrick Hansen	1962	225
	East Bay Cleft Parent Guild 4916 Scotia Ave. Oakland, California 94605	Mrs. Benny Tapscott	N.g.	N.g.
	Sacramento Cleft Palate Club 3905 Cresta Way Sacramento, California 95825	Mrs. Jerry D. Sutherland Mrs. Vernal Kimmey	1970	23
	Santa Clara County Cleft Parent Group, Inc. 5702 Goldfield Drive San Jose, California 95123	Mr. & Mrs. Jerome L. Rubin Mrs. Ellen F. Leal	1963	225
Colorado	Cleft Lip/Palate Parent's Group 1120 South Butler Way Lakewood, Colorado 80226	Mrs. Elizabeth J. Pruett	1972	150
Iowa	Cleft Lip and Palate Club 2438 Hawthorne Drive Cedar Falls, Iowa 50613	Mrs. Patricia J. Moes	1968	91
	Cleft Lip & Palate Group of Central Iowa 6412 University Des Moines, Iowa 50311	Mrs. Paula Staggs	1972	33
	Cleft Children Family Council of Souix- land, Inc. 20 Congress Sioux City, Iowa 51106	Mrs. Karen Lien Mrs. Robert Wiskus	1973	25
Massachu- setts	Prescription Parents for Cleft Palate, Cleft Lip Children 20 Ash Street Boston, Massachusetts	Mrs. Donald Delaney	1972	N.g.
Michigan	Cleft Lip & Cleft Palate Parents' Asso- ciation 509 South State Caro, Michigan 48723	Rev. & Mrs. Raymond Prough	1968	25
	Oral Cleft Parents Group, Speech and Hearing Clinic Western Michigan University Kalamazoo, Michigan 49001	Dr. Clyde R. Willis	N.g.	N.g.
New York	Cleft Palate Parents Council, Suffolk Chapter 13 Lincoln Street Babylon, New York 11702	Mrs. Florence Gruenberg	1969	114
	Cleft Palate Parents Council Brown-Westchester Chapter 9B Earhart Lane Bronx, New York 10475	Stan Siflinger	1972	55
	Cleft Palate Parents Council 20 Bent Lane Levittown, New York 11756	Irv J. Fischer	1968	165
Pennsylv- ania	Cleft Palate Parents Association 215 Chapel Crest Terrace Pittsburgh, Pennsylvania 15238	Mrs. Lois Tomlinson	1972	112
Texas	Parents Society for Cleft Palate Children P.O. Box 1167 Fresno, Texas 77545	Mrs. Marsha Gaines	N.g.	N.g.

* N.g. = Not given.

3. "it was started by the president who had been in a group in _____; we went into action with a few interested people under the auspices of the University Birth Defects Center."
4. "my daughter was this area's March of Dimes poster child as part of the publicity. I had a TV interview which Mrs. _____ watched and then contacted me; we started from there."
5. "to help inform new mothers of how to handle their cleft palate child, inform local hospitals and doctors on this condition, and for us to learn more about it from speakers, etc."
6. "to explain and exchange ideas regarding our cleft palate children, also to educate the public, and offer each other moral support."
7. "patterned after the _____ group, our group was formed to assist those parents in this immediate area rather than require them to drive to _____."

It is of interest to note the similarity of objectives between parent and professional groups. The American Cleft Palate Association is composed of accredited professionals who have displayed an interest in the study and/or treatment of cleft palate. The objectives of the Association (2) are:

1. to encourage scientific research in the causes and nature of cleft palate and cleft lip.
2. to promote the science and art of rehabilitation of persons with cleft palate and associated deformities.
3. to encourage cooperation among, and stimulation of, those specialists interested in the rehabilitation of cleft palate persons.
4. to stimulate the public interest in, and support of, the rehabilitation of cleft palate persons.

The groups were initially organized as a result of parents "getting together" on an informal basis; at the suggestion of a physician, speech therapist, or social worker, and/or in response to a newspaper story. All the groups except three have a constitution and by-laws ($N = 12$). Eight are incorporated as nonprofit tax exempt corporations, and one is in the process of incorporating. Nine of the groups do not have an institutional affiliation; seven others are affiliated with crippled children's societies, universities, rehabilitation centers, or hospitals.

Only one parent group did not know of any other groups. The California, Iowa, and New York organizations were aware of the existence of other groups irrespective of geographical location, and were in communication with each other. Some of the groups are outgrowths of other groups. For example, the groups in California, Iowa, and New York have "helped other groups get started."

In March 1972, a state wide conference of California Cleft Guilds was held in San Jose. Four parent groups were included in this conference: Santa Clara County Cleft Parent Group, Incorporated, Cleft Parent Guild of Los Angeles County, Sacramento Cleft Palate Club, and Cleft

Palate Parent Guild of Claremont. The conference program included both lectures and discussions of the following topics: background and history of each group; education, including general meetings; distribution of literature, speech facilities; sources of parent referrals; services and social activities offered by guilds; special feeding devices; cleft assistance fund program; fund raising; the need for a cleft palate clinic on the west coast, and future objectives. A summary of the program has been published (15) and is available from the Santa Clara County Cleft Parent Group, Inc.

MEETINGS. Meetings range in frequency from monthly ($N = 8$) to semiannually ($N = 2$). The majority of groups ($N = 10$) report that attendance at meetings fluctuates. Attendance appears to be related to a variety of factors, including interest in the program, weather conditions, availability of child care, distance, etc.

One group reported that some of its members drive as far as 60 miles to attend monthly meetings twice a year. This, in part, served as the impetus for the establishment of one of the other parent groups, i.e., to provide an organization within the immediate area. Child care-baby sitting is provided by the Teen Group of one organization. Another group has fluctuating attendance at meetings since they have morning "coffee Klatches" for mothers, and evening meetings that include fathers.

The meetings of the majority of the groups follows one or another version of the program-speaker, discussion, business, social-hour format. The only real departure from this format was a group that usually holds very informal meetings such as pot-luck suppers and picnics, with an occasional speaker or movie.

Generally, board members plan the educational portions of meetings, although in some groups, the meetings are planned in consultation with group members and professionals. One exception is the Santa Clara County Cleft Parent Group, Inc., which has established a rotating cycle for educational subjects in which the cycle is completed approximately every eighth meeting. The subject matter includes plastic surgery, orthodontia, speech therapy, otology, genetics, child psychology, and parent-panel discussions. Another group indicated that they were going to utilize Santa Clara's "already tried formula."

The needs of members or interest in specific speakers are usually determined by suggestions and discussion by group members. The speakers are usually professionals involved in cleft palate rehabilitation such as otology, gynecology, dentistry, orthodontia, pediatrics, social service, genetics, speech pathology, audiology, and child psychology. One group reported that their guest speakers had included cleft palate adults.

Information about the groups is disseminated in a variety of ways. Many groups rely on "word of mouth," while others use mass media such as letters, radio announcements, newspaper articles, and pamphlets placed in hospitals. Other ways in which communities are informed about groups are through publicity committees, individuals (parent members, doctors,

nurses), and organizations (cleft palate centers, speech and hearing clinics, crippled children's services, medical auxiliaries).

FINANCE. Funds to support parent group activities come primarily from membership dues, fund raising activities, and, in a few instances, from contributions. Annual membership dues range from nothing to five dollars. Expenses of the groups include newsletters, pamphlets, speakers, donations to hospitals and cleft palate programs, plants or gifts for new mothers, social and fund raising activities, and feeding equipment.

GOALS AND SERVICES. It appears that the goals and services of parent groups are primarily related to (a) parent education and counseling, (b) public education, and (c) clinical treatment. Here are the purposes and goals of four groups:

1. To provide for dissemination of information for public and professional education for the better habilitation of children with cleft lip and palate; to lend support to new parents through an exchange of ideas and methods for the care of their infant; to create an awareness of facilities available for assistance (20).
2. To give support to the university cleft palate center in their education and research programs; to undertake activities to benefit cleft palate children, their parents, and the communities in which they live; to give parents an opportunity to meet and discuss subjects of mutual interest (21).
3. To render educational services to those concerned with cleft lip and/or cleft palate (14).
4. To share experiences, problems and joys with others who might be in the same situation; teach new mothers and fathers care of cleft lip and cleft palate children; write a booklet which would aid the new mother in caring and feeding the child with a cleft; to teach those in the community who need to be informed or would like to learn more about cleft lip and cleft palate; to learn more about caring for the child with a cleft in certain fields such as speech therapy, orthodontics, physical, spiritual and mental growth; to make people aware of the facilities available for habilitation of the cleft individual and its importance (6).

The California Cleft Guilds (15) have described the ways in which cleft parent groups can and have helped new parents as follows:

1. Visiting the home, preferable in teams with a male member to talk to fathers.
2. Give positive feedback to the mother on how well she is holding up (even if she is really a bit shaky).
3. Make available various feeders and other educational materials and literature.
4. Support the mother or father who has no spouse.
5. Tell parents of the various medical and financial services which may be available to them.

6. Give parents a realistic picture of what is going to be involved in the next dozen years or so.

Future objectives of the California Cleft Guilds (15) include (a) having a yearly conference of all existing cleft parent groups in the state, and (b) unifying groups for stimulating desired legislation. Immediate as well as future objectives have been defined by the Santa Clara County Cleft Parent Group, Inc. (14). Their immediate objective is a medical assistance fund to aid middle income families who either cannot qualify for crippled children's services or do not have private sources to meet necessary medical costs. Future objectives include the initiation of (a) chapter parent groups in Alameda, Santa Cruz, and San Mateo counties, and (b) an oral-facial-communicative care and treatment clinic in Santa Clara Valley.

Table 2 lists the services provided by fifteen parent groups. All of the groups provide for communication exchange among members. It is of interest to note that six of the groups provide funds to support individual costs of habilitation. A number of the groups have members who assist in the public education program by speaking to service organizations, speech and hearing clinics, hospitals, health departments, nursing schools, and/or elementary schools. Additional services provided by two of the groups include (a) a 24-hour telephone service for anyone needing help or advice, and (b) a complete cleft palate feeder supply which is available on loan.

All twelve parent groups that have newsletters indicated that they would be interested in exchanging newsletters with other groups. Thirteen of the groups use pamphlets or books for parents of children with cleft palate. Many of the groups use more than one publication. These publications are summarized in Table 3. *Your Cleft Lip and Palate Child: A Basic Guide for Parents* was used by ten groups: *Bright Promise*, *Steps In Habilitation for the Cleft Lip and Palate Child*, and the *Road to Normalcy for the Cleft Lip and Palate Child* were used by seven. All other publications were used by only one or two groups. Wylie and McWilliams (26) reported that *Bright Promise* was the parent publication used most

TABLE 2. Services provided by fifteen parent groups.

<i>number</i>	<i>service</i>
15	information exchange between members
14	meetings
14	parent education
13	counseling of new parents
12	community—public education
12	newsletter
8	counseling
6	funds to support individual habilitation costs
4	distribution of literature to hospitals and/or public libraries
2	library for members

TABLE 3. Pamphlets and books used by ten parent groups. All materials were submitted by groups to authors for review.

<i>title</i>	<i>author(s) and degree</i>	<i>publisher</i>	<i>publi- cation date</i>	<i>no. of pages</i>	<i>emphasis</i>	<i>no. re- port- ing</i>
Your Cleft Lip and Palate Child: A Basic Guide for Parents	Gilbert Snyder, M.D. Samuel Berkowitz, D.D.S. Kenneth Bzoch Ph.D. Sylvan Stool, M.D. Eugene McDonald, D.Ed.	Mead Johnson & Company, Evansville, Indiana 47221	N.g.*	14	general	10
Bright Promise		National Society for Crippled Children and Adults, Chicago, Illinois 60612	1959	21	general	7
Steps in Habilitation for the Cleft Lip and Palate Child	Samuel Berkowitz, D.D.S.	Mead Johnson & Company, Evansville, Indiana 47221	1971	13	facial growth and development	7
The Road to Normalcy for the Cleft Lip and Palate Child	Samuel Berkowitz, D.D.S.	Mead Johnson & Company, Evansville, Indiana 47221	1971	13	types of clefts, surgery, feeding	7
Cleft Lip and Cleft Palate (Nursing Education Aids No. 11)	N.g.	Ross Laboratories, Columbus, Ohio 43216	1962	2	types of clefts	2
Parents' Guide to Cleft Palate Habilitation	Aaron Bleiberg, Ed.D Harry Leubling, M.A.	Educational Publications, New York, N.Y. 10025	1971	163	general	2
An Open Letter to The Mother of a Cleft Palate Child	John Bryant, M.A.	Cleft Palate Parents' Council, Babylon, N. Y. 11702	N.g.	3	general	1
Cleft Lip and Cleft Palate Club	N.g.	Cleft Lip and Palate Club, Cedar Falls, Iowa 50613	N.g.	11	parent group orientation, types of clefts, pre- and post-operative care	1
Feeding Children with Cleft Lip and Palate	N.g.	Washington State Department of Health, Olympia, Washington	1966	12	feeding, diet	
Feeding Your Cleft Lip and/or Palate child	Laura Lipski, R.N.	Cleft Palate Parents' Council, Babylon, N. Y. 11702	N.g.	3	feeding	1
Helping Your Child Speak Correctly (Public Affairs Pamphlet No. 445)	John Bryant, M.A.	Public Affairs Pamphlet, New York, N. Y. 10016	1970	20	speech	1
No One Else Can Be as Helpful	Virginia Apgar, M.D.	Today's Health (American Medical Association)	1969	4	parent groups	1
Normal Lives for "Crippled Mouth" Victims	Jean Carper	Today's Health (American Medical Association)	1968	4	general	1
Nursing Care of Babies with Cleft Lip and Palate	N.g.	Nursing Times, Booth Hall Hospital for Children, Manchester, England	N.g.	5	feeding, nursing care	1
Services of the Cleft Parent Group	N.g.	Santa Clara County Cleft Parent Group, Inc. San Jose, California 95123	N.g.	7	parent group orientation	1
Speech	Laura Lipski, R.N.	Cleft Palate Parents' Council, Babylon, N. Y. 11702	1970	2	speech	1
Summary of State Wide Conference of California Cleft Guilds	N.g.	Santa Clara County Cleft Parent Group, Inc., San Jose, California 95123	1972	10	parent groups	1
To the Citizen if Your Neighbor has a Cleft Palate	N.g.	Lancaster Cleft Palate Clinic, Lancaster, Pennsylvania	N.g.	2	citizen responsibility, available facilities	1
To the Parent if Your Child Has A Cleft Palate	N.g.	Lancaster Cleft Palate Clinic, Lancaster, Pennsylvania	N.g.	3	general	1
To the Teacher if Your Pupil Has a Cleft Palate	N.g.	Lancaster Cleft Palate Clinic, Lancaster, Pennsylvania	N.g.	2	teacher responsibility	1

* N.g. = Not given.

frequently by cleft palate clinics. Grabb (8) recommends three publications to parents of cleft lip and palate children in the following order: *Your Cleft Lip and Palate Child*, *Bright Promise*, and *The Child with a Cleft Palate* (22). Bleiberg and Leubling (4, p. 98-99) recommend several books and articles including McDonald's *Bright Promise*. The information covered in early parent counseling sessions by Bzoch (5) usually includes information covered in *Bright Promise* and *Your Cleft Lip and Palate Child*.

The results shown in Table 4 indicate that ten or 67% of the groups are interested in a national organization for parents of cleft palate children. Possibly the prerequisite to a national organization would be an exchange of newsletters between parent groups. Recently, there have been some "events" geared toward national organization of parent groups. The American Cleft Palate Association has been hampered in past efforts to include parents because of its membership requirements. At the 1973 ACPA convention the American Cleft Palate Educational Foundation was established. The Foundation will have "public" members and hopefully attract the interest and support of parents. One parent group has a national chairman and indicates that "at this point we have been invited to appear on a national television show which will automatically swell our ranks, hopefully with participating groups forming in most of the United States."

According to the parent groups the most important current needs in cleft palate habilitation are, for the most part, related to (a) public and professional education and communication; (b) availability of facilities and services, and (c) financial assistance. The following are needs as identified by nine parent groups:

1. In our area—lack of communication among doctors with each other and with parents. Also facilities are much to be desired here, in all areas—speech and hospital care. No children's hospital within a close radius—general hospital staffs not trained in care and treatment of cleft child after surgery nor trained in the feeding of a cleft palate infant in newborn nurseries. Much needed—a cleft palate, or oral, facial, communicative care and treatment center, for all diagnostic and medical care, all records under one roof, on the west coast.
2. Informing hospitals, doctors, new parents, etc. about how to feed the

TABLE 4. National organization for parents.

<i>response</i>	<i>N</i>	<i>%</i>
yes.....	10	67.
possibly.....	1	6.5
no.....	3	20.
no answer.....	1	6.5
 totals.....	 15	 100

- babies, information on the cleft lip and palate condition, and the facilities that are available for the child.
3. Financial assistance to families who are not on a welfare or medicaid level but who do require aid, and better communication between doctor and parents.
 4. The equalizing of management of all cleft palate children regardless of where they lived, in terms of national geographic location. We feel that there is a great advantage to the TEAM approach for treatment. To pool research data from many centers in order to reduce bias in the results. That the State fee scale have adequate adjustments so that treatment is fully covered.
 5. Financial aid in all areas, particularly speech therapy and orthodontics. These two programs are not included in health insurance programs or by State aid. Reaching new parents within a month after delivery. Research.
 6. Speech correction. Making the public aware of such people.
 7. Research—and you can do some through your questionnaire but also experimental research with primates. Genetic counseling. Education—of others and of our children telling them to be frank and verbal about their clefts.
 8. Financial assistance to parents to cover major medical expenses not covered by medical insurance, for example, orthodontia and speech therapy. Psychological counseling of parents at a nominal fee or “free” when infant is first born. Later on counseling for the child to cope with difficulties of speech impediment, facial disfigurement, etc. Better education for medical profession—especially pediatricians on complexity of cleft palate child’s care.
 9. To be able to know where to go for help: (a) state hospitals; (b) where is feeding equipment available, and (c) people don’t know where to go for different services.

Summary and Conclusions

A survey of cleft palate parent groups was undertaken during 1972 and 1973. Questionnaires were sent to all known parent groups. The listing was derived from an announcement in the Cleft Palate Journal and parent groups. Returns were received from fifteen or 75% of the twenty respondents. The data shows that there is (a) a total membership of over 1,344; (b) the majority of parent groups are located on either the west or the east coast, six in California and three in New York; (c) the goals and objectives of the parent groups are quite similar to those of the American Cleft Palate Association, and (d) the parent groups primarily provide informational services for members, parents of newborn cleft palate children, and the general public. The information reported herein should provide guidelines for future activities, such as a national organization, as well as implications for professionals currently involved in cleft palate

habilitation. The professional implications include (a) provision for improved public and professional education and communication; (b) guidance as to the availability of services as well as the possibility of expanded services, and (c) financial assistance to families not covered by insurance or current state programs.

Acknowledgement: The authors are indebted to several people for completing the questionnaire and providing materials. Among these are: Ruth Autz, Majorie Barnoncini, Evelyn Boice, Marsha Gaines, Irv Fischer, Mr. and Mrs. Patrick Hanse, Karen Lien, Betty Jane McWilliams, Patricia Moes, John and Priscilla Mizerak, Rev. and Mrs. Raymond Prough, Elizabeth Pruett, Barbara Rubin, Norman and Gwen Sanders, Stand and Joyce Siflinger, Paula Staggs, Suzanne Sutherland, Lois Tomlinson, and Edith Wiskus. The contribution of M. Don Ryan, Director, Speech and Hearing Clinic, Texas Woman's University, for his help in making this project possible is gratefully acknowledged.

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