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ABSTRACT

This instructional kit is intended to increase understanding and empathy within the school community to the needs of the student who has a facial disfigurement. For kindergarten to grade 3, the kit provides information for discussion and activities. For grade 4 through secondary school, an associated video features young people who have a facial disfigurement discussing their experiences and feelings. The kit includes a teacher's guide to the unit, background information covering effects of facial disfigurement at various life stages, a sample letter to parents, suggested group discussions, suggested creative activities, self esteem reinforcement techniques, a list of 14 resources for parents, teachers and young adults and 8 resources for children. Also provided are sample copies of the newsletter, "AboutFace" which report on activities of this support and information network concerned with facial disfigurement, an AboutFace brochure, and an order form. (DB)

We all have different faces

AboutFace

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INTRODUCTION

"We all have different faces" is a school education program which was developed to increase understanding and empathy within the school community to the needs of the student who has a facial disfigurement. Using this program as a guide, parents and teachers can work together to create a supportive environment.

For Kindergarten to Grade 3, this kit provides information for discussion and activities. These offer an opportunity for open dialogue and for questions or comments which students may have. From Grade 4 through secondary school, "The Beauty Within" is a video which provides an additional resource. It features young people who have a facial disfigurement discussing their experiences and feelings.

A workshop program is available through AboutFace to train interested volunteers in conducting presentation of this community program.

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TEACHER'S GUIDE TO UNIT

An individual's school environment plays a prominent role in the socialization process. A student with a facial disfigurement is obviously "different" from his peers. Teachers in the school system can assist in providing a positive socialization experience for such a child by helping him cope with his difference, and by helping his peers to be sensitive and understanding. As severe facial disfigurements are quite a rare occurrence, most people have little experience in interacting with others who look dramatically different. A common response is often one of ambivalence and discomfort toward someone who is facially disfigured. It is important to remember your comments, expressions and behaviour will communicate a great deal to your students. They will be able to tell if you feel at ease with the subject.

Getting in touch with your feelings will increase your level of comfort and improve the quality of the educational experience for your students. Think back to the first time you saw someone who was facially disfigured. How old were you? How did you feel and react to the person? What did the experience mean to you? What would it be like to be in their shoes? By reflecting on these sorts of feelings you can begin to gain some understanding of facial disfigurement.

There are many books and articles written about the psychosocial aspects of facial appearance. Bibliographies of useful material for adults and children are included in this kit. Parents of students who are facially disfigured may have concerns about their child's participation in activities. They may be afraid that their child will experience rejection from peers or suffer from a poor self-image. Parents are instrumental in providing a positive learning experience for their child. Some parents will assist in helping the teacher to plan a particular activity.

While many parents are pleased that their child can learn to accept differences and acquire a positive attitude towards children who look different, other parents of children with a normal facial appearance may have some concerns. They themselves may feel uncomfortable with a person who looks very different. They might wonder how to answer their children's questions. Teachers may find it helpful to introduce the concept of facial disfigurement to parents by means of a letter explaining the teaching unit (see page 4). The teacher might also organize a parent-teacher meeting to discuss parents' questions and concerns.

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How To Use This Kit Effectively

1. Read the background information.
2. Investigate other community resources, especially your local AboutFace chapter, for further information, brochures, etc.
3. Familiarize yourself with some of the suggested reading.
4. Speak to appropriate staff members for co-operative planning for the unit, e.g. teacher-librarian, special-education teacher, appropriate consultants.
5. Send home a copy of the sample letter to inform parents (see page 4).
6. Use the suggested activities.

The teacher should be reminded that this kit is to be used as a starting point, and may be added to as new ideas emerge. There is room for creativity, exploration and application to other areas of disability. Most important is that the focus be interactive, the children create the activity with the help of the teacher. A trained volunteer may be available in your community to assist you. Contact AboutFace.

BACKGROUND INFORMATION

Background Information

The recent literature on the psychology of appearance has revealed that socially desirable qualities such as intelligence, honesty and friendliness have been attributed to attractive individuals in the assumption that "Beauty is Good". The theory is that the physically attractive person's life will be happier and more successful. Attractive people are generally more socially active and assertive and have higher self esteem than less attractive people.

Facial disfigurement can be caused by a congenital deformity, or as the result of an injury or illness (such as cancer). Depending on the condition, the degree of improvement possible with surgical treatment will vary. Due to the nature of some abnormalities, surgery may not be an option for some individuals. One of the challenges of being disfigured is developing self-acceptance, and integrating comfortably with society. Counselling on an individual basis, a family approach, or group work with a trained professional can help, but coming to terms with a facial disfigurement is a lifelong process. Ongoing communication with others facing the same concerns through involvement with a support group can offer the individual the opportunity to share experiences with someone who really knows how he/she feels.

Teachers can assist students who are disfigured to integrate successfully and reach their potential, if they are aware of specific "pressure points" which families have to face.

Birth

Research indicates that parents are generally unprepared for the shock of the birth of a child with a facial abnormality. While parents' reactions depend on their personalities, backgrounds, strengths and weaknesses, and coping strategies, it is generally thought that parents must grieve the loss of the "perfect child" before they can invest in their child and focus on treatment, i.e. what can be done, not what has happened. The extended family can provide a supportive environment for parents d child.

Preschool Years

We know that the sooner the child with the facial deformity has the opportunity to interact with other children, the better. Attractiveness is a crucial factor in social adjustment, and stereotypes and prejudices are not limited to adults. Research shows that preschoolers prefer the company of attractive peers, as they are viewed as smarter, more friendly, and better behaved than unattractive children. Preschool children judged as unattractive are often assumed to be either more aggressive or less intelligent than their peers. While this may be so, young children with facial deformities seem to cope better than do older children, adolescents and young adults. Preschool and school age children's lives are centered in their homes, neighborhoods and schools. Within these realms, the children are generally known and accepted.

During the preschool years, parents can provide a supportive and encouraging environment which allows the child to develop a positive self-image. As the child ventures from home, parents will have less control over this environment, and the wise parent will prepare the child for questions from other children. Investigators suggest that children with facial deformities do not perceive themselves as different until approximately the age of four.

Early and simple communication between parent and child is the key to self esteem at this age. Clear explanations about the nature of the problem followed by age-appropriate explanations, the child can use when questioned, will prepare him/her for the inevitable inquiries from others. Actually role-playing these with an adult can help develop an early sense of competence and build self confidence in new social situations.

School-Age Child

The school environment provides the opportunity for contact with other children, and development of relationships. The peer group is usually very quick to identify and accept any limitations, and also to see past the facial difference. However, some children with facial abnormalities have been found to be more withdrawn and inhibited in the classroom than other children. In school there is greater stress on competition and attractiveness as compared with the secure home environment. The child who is facially disfigured may feel that he/she cannot compete in terms of social or athletic achievement. Each change of environment, such as changing schools or meeting strangers, places a renewed stress on a child who is facially disfigured. Maximum stress occurs when the child leaves his home environment to go to school.

During the elementary school years, the child's peer group gradually becomes more important than parental influence and there is increasing pressure to fit in with peers. The child who looks different may be subjected to teasing and various non-verbal negative reactions such as other children avoiding physical contact. It is essential that the child be prepared to deal with this, acknowledge negative reactions, recognize his/her own anger and deal with the situation constructively. Some children cope by educating their classmates, while others rely on their sense of humour, their ability to achieve or by demonstrating their specific talents. Self-esteem is determined mainly by the child's ability to feel positive about at least one aspect of his or her life. "Everybody needs to be a star somewhere". It is critical that parents explain their child's condition to the teacher. Teachers and other professionals can then help provide the opportunity for positive experiences for the student.

Adolescence

Adolescence is a challenging period for any young person, and for the individual with a facial disfigurement it can be particularly difficult. The world expands dramatically during adolescence, with attendance at larger schools and greater freedom within the community. Within this larger environment, the teenager is not necessarily known or automatically accepted and the stigma attached to looking different can challenge even the well-adjusted teen.

As the child reaches puberty, appeal to the opposite sex becomes important. Insecurity and self-doubt go hand in hand with the changes in physical appearance, and the individual with a l disfigurement may experience a sharp decrease in self esteem as he/she realizes the broad impact of their facial difference. Concurrently the teen may be forced to acknowledge any limitations of medical treatment. In spite of these issues, most students maintain their academic standing, but lag behind in emotional and social development. Many stick close to home and may not be involved in mixed group activities like dating. Some cope by appearing to be indifferent to the opposite sex, focusing instead on academic or athletic achievements. Life becomes easier as peers mature and begin to see the person behind the face.

Facial disfigurement has an impact on peers' and teachers' perceptions of the adolescent. The negative self image, lowered self-esteem, and problems in social adjustment associated with facial deformities are not only recognized by the individual but may be reinforced by peers and people in authority. Teachers can help by encouraging students in their areas of strength, and offering them the opportunity to demonstrate their abilities among their peers or as a role model for a younger person.

Adult

The developmental tasks of young and middle adulthood are focused on career choice and intimate relationships. Individuals may seek surgery at this stage because they feel their appearance restricts their career choices and limits their opportunity for dating and marriage. The adult with a facial disfigurement has a greater chance of being socially isolated than his more attractive counterpart. Having a supportive family and friends are important factors in continued adjustment whether or not surgical treatment takes place. A developed sense of competence in career-related activities is also important.

A SAMPLE LETTER TO PARENTS

Dear Parent,

We have recently been talking and learning about how we are the same and how we are different from one another.

The students have been learning about people with facial disfigurement. Instead of accentuating differences in appearance, we talk about the similarities in feelings and activities that are shared by all people. We will be doing some related activities to expand on our discussions such as dramatic play, stories and creative artwork.

Teachers and parents can work together to foster and support positive attitudes toward individual differences. We invite you to share your ideas with us.

Please feel free to contact me at...

Sincerely,

SUGGESTED GROUP DISCUSSIONS

Aim:

a. To raise awareness to the emotional needs of the facially disfigured.
b. To encourage acceptance of the facially different.

1. Group Discussion about Appearance

This should be an informal group with students seated either on the floor, or in chairs grouped to facilitate conversation. The discussion should last no more than 10 to 15 minutes, depending on the attention of the group. To lead the discussion, the teacher might focus on the uniqueness of every human being. The teacher might begin by showing the students pictures of different faces, and asking them for ideas about how people are different and how they are the same.

Discuss reasons for difference in appearances:

1. Birth defect
2. Accident
3. Disease
4. Natural Process of Aging

How do you feel about the way you look?

2. Group Discussion about Feelings

- We all have feelings. We can feel happy, sad, angry scared or excited.
- Sometimes you can tell how a person is feeling just by looking at his/her face.
- What kinds of things make you feel happy? (sad, angry, afraid, excited)
- Even though we look different, we have the same feelings.
- Even though we look different, we like the same things.
- Even though we look different, we like each other.
- It's good to talk about your feelings to let others know how you feel.
- It's nice to share our feelings with others. It's an important way for us to get to know each other.
- Some people cannot show their feelings as easily because their faces look very different. Have you ever seen somebody whose face was so very different? You might wonder why does that person look that way. Some people like to talk about it, and some people don't. They might feel shy or afraid that others won't like them because they look different.
- A person's face might look very different if they have a scar from a burn or a fall or a birthmark. The teacher might say, "I have a scar on my arm, do any of you have a scar?" What happened? It can happen to anyone. Has anyone ever burned himself? Sometimes you can get a scar from a burn too. A burn can happen to anyone. Does anyone have a birthmark? A person's face could look really different because of an accident, or because of a birth defect. And, because the face is different, the feelings that show there may look different to someone who is not used to the person. (Examples: a child with a cleft lip and palate may look angry because of a scar on his/her lip; a person with facial nerve damage may not be able to smile). The focus for the teacher is that for whatever reason someone looks different, it could happen to any of us through a barbecue fire, scalding or car accident. In doing this, the teacher is able to normalize the experience for children.

Following the group discussion, the teacher will involve the students in activities to further develop their understanding of facial disfigurement. Ten to twenty minutes should be allowed for these activities, but this is flexible. After the activity, there should be a concluding statement to summarize the students' thoughts and feelings, and to answer any questions. The teacher should be flexible in allowing them to express their perceptions both at the time of the activity, and at other times. The teacher may utilize other themes and activities throughout the year, repeating and/or building upon them when appropriate.

SUGGESTED CREATIVE ACTIVITIES

Aim:

To allow the students to explore their feelings and the feelings of others in a creative or dramatic way.

1. Drawing My Face

Materials:
Paper, crayons, markers, paints, other drawing materials. Procedure:

1. Have the students draw a picture of their own faces, making them as detailed as possible. The teacher should join the students in drawing a picture of his/her face.
2. Display the pictures in a "Rogues Gallery" in the classroom or school hallways.
3. Encourage the students to talk about how we are the same, and how we are different.
4. For senior students, discuss relationships of facial features, i.e. spaces between features, symmetry.

2. Popsicle Stick Faces (for younger classes)

Materials:
Popsicle sticks, paste, paper plates or construction paper, crayons or markers, magazine pictures selected to elicit various feelings (spinach, ice cream cones, a broken toy, etc.)
Procedure:

1. Have the children draw a picture of one happy face and one sad face on either side of the paper plate, or cut and draw face shapes out of the construction paper.
2. Paste the faces to the popsicle sticks.
3. Show magazine pictures to the children and ask them to tell how they feel about each picture by holding up the appropriate face.
4. Ask the children to tell why they felt a particular way about a specific picture.

3. Discovering My Friends

Procedure:
Have students pair up with a classmate. Get them to interview each other to find out what kinds of things they like (i.e. peanut butter sandwiches, skateboards, when someone says something nice about you, bicycling), and don't like(i.e. being in the dark, when someone hurts your feelings). After students feel they know each other well enough, have them present each other to the rest the class.

4. The Outside is Different, the Inside is the Same

Materials:
A plain face mask which shows no emotion, e.g. small mask for eyes or neutral theatrical mask.
Procedure:
The purpose of this activity is to summarize and integrate the material presented by the teacher. Have the students sit in a circle around you. The teacher puts the mask on and off his/her face and talks about his/her feelings, things she likes, doesn't like, hopes for, etc. The ide [illegible] that even though the teacher's face is different with the mask on, the teacher with or without the mask still likes/dislikes the same things (peanut butter sandwiches riding a bicycle, when people say nice things to you). Students will quickly realize that the "outside" may look different, but the "inside" or feelings are the same for everyone. The students may want to take turns trying on the mask themselves.

5. Research Project

Investigate and report on one of the following subjects:
Port Wine Stains
Burn Care
Plastic Surgery
Laser Surgery
Neurofibromatosis

6. Show one of the following movies (for older students)

The Elephant Man
The Hunchback of Notre Dame
Mask
Roxanne
Cyrano

7. Read Storeis

Highly recommended for younger students is "Rosey...the imperfect angel" by Sandra Lee Peckinpah (see separate bibliography).

8. Community Service

Interested students could become involved on an individual basis in the "Buddy" helping system where the student goes into a school for the physically or mentally disabled to help out occasionally, or volunteer time to the local hospital.

SELF-ESTEEM REINFORCEMENT TECHNIQUES

Self-esteem is a personal judgement of worthiness that is expressed in the attitudes an individual holds towards himself.

It is a reflection of what the individual thinks others' judgement is of him

Factors that Shape and Affect Self-Esteem

A. The respect, acceptance and concern of significant others.

"Significant others" are people whose opinion (particularly of ourselves) matters to us. As an individual matures, those who are considered significant others change from immediate family members for the very young child,to teachers for the school-age child.The peer group is most important for the adolescent when acceptance and integration depend on being the same as everyone else. The greatest area of exposure is school, so the primary site of this aspect of self-esteem may be the classroom.

B. History of successes

What has happened in the past? This forms a basis in reality for self-esteem. Success is measured in terms which depend on developmental stages: from development of physical skills, to largely social evaluations by teens.

C. Values and aspirations

These are set by an evaluation of (B). In other words, the more successes we have, the higher our aspirations and expectancies.

D. Problem solving

Self-esteem will reflect whether difficulty is handled as a devaluation or positive learning experience.

Disability and Self-Esteem

For disabled individuals, acceptance and integration may be more difficult, and achievements may be dictated by physical or mental impairment, or time missed from school for medical reasons. The type of disability and how it is accepted by the individual and his family are other factors which affect self-esteem.

a. Simple vs. complex disability
— The degree to which the disability interferes with daily activities and is correctable.

b. Visible vs. secret disability
— Is the problem obvious or hidden? While this is not an indication of severity, a hidden problem may involve fewer stressful explanations, but be a greater emotional burden.

c. Onset
— Is the disability acquired or a birth defect? In other words, have the coping mechanisms been in place for a long time or are they new?

d. Progressive vs. stable disability
— Treatment time and hospitalization affect acceptance by the individual and his peers.

e. Severe vs. mild or marginal disability
— A less severe problem may appear "normal" and evoke feelings of indifference or less understanding for behaviour out of the norm. More severe disabilities may result in rejection, or feelings of increased pity from others.

Behaviour changes

Teachers can be alert to various changes in behaviour which may indicate a problem with self-esteem at any stage. The peer group is a key indicator, with attention to a shift to a smaller peer group and lack of participation in extra-curricular activities. This can swing to the extreme of no friends, or a delinquent peer group. Clowning and ridicule or teasing from others also signal difficulty. A change in academic performance with a drop in marks or a reluctance to participate in class is another behavioural indicator of poor self-esteem.

How to Foster Self-Esteem in the Classroom

Using the four areas of importance discussed above, teachers can maximize positive experiences in the classroom, thus enhancing self-esteem.

A. Significant others' respect, acceptance and concern

1. Stress similarities with others, point out and emphasize.
2. Encourage a sense of belonging to a group. This can be approached through the use of sub-groups—clubs, small group activities, the Buddy system, etc.
3. Personalize your approach: use the individual's name, make eye contact. Personal attention adds to the feeling that the individual receiving it has worth.
4. Emphasize the importance of manners to social interaction—e.g. table manners, shaking hands. Solving and adapting the disability will ease integration and acceptance.
5. Peer education will give others the opportunity to ask questions and have them answered correctly. There are different ways this can be handled:
   —Guest speakers: most effective if this is someone with the disability who can talk candidly about his own experience.
   —Public speech: for the bright, verbal student, an opportunity to explain and share.
   —Research science project: less personal, more objective.
   —Public health, community resources: use of resources from the local hospital, support groups, puppets, film strips.

- Above all, the most important result of peer acceptance and education would be development of empathetic behaviour—an understanding that it is normal to stare and feel awkward. Helping others get past those feelings, will enable them to relax in a social interaction.

B. History of successes

1. Steer the student toward experiences likely to be positive and successful. The possibilities are only limited by the imagination!
2. Manipulate an experience or create a situation for success. For instance, putting the disabled student in a tutoring situation where a particular expertise and experience can help someone else.
3. Incorporate successful strategies into other areas to give a greater incidence of success; e.g. If a student is good in Art but not Geography, have him use his drawing skills to illustrate a map lesson—in his own workbook, or as a display for the whole class.

- Remember to reinforce positives!

C. Values and Aspirations

1. Encourage expression of thoughts, feelings and needs, secret dreams. Literature can be helpful to elicit discussion.
2. Make the individual aware of disabled role models: authors, athletes. Stress famous people (e.g. Einstein), who were thought to be limited.
3. Encourage career skills as an extension to social skills. Schedule aptitude testing, teach how to apply for a job, how to "unfreeze" a job interview, help the individual develop answers for a perspective employer about disability and stress his strengths. This can be done very effectively through role play situations.

D. Problem Solving

Teaching problem solving, and evaluation of situations will increase the opportunities for experiencing a sense of control over life, which in turn builds self-esteem. Offering choices is an important step in this process.

a. Identification of the problem
—Is the individual aware there is a problem, or is it being denied?
—Have the student describe the situation as he sees it.

b. Factors
—What is involved in the problem—assessment by the student and others.

c. Solutions
—"Brainstorming" of possible solutions.
—Development of alternate behaviour plan.
—Identification of best solution.

d. Re-evaluation and assessment
—Important step for allowing for a second chance
— Give the new behaviour plan a time limit for review.
—It is also important that the solution belong to the individual. This gives room for independence and responsibility.

- Guide problem solving in small, manageable steps — offering more chances for improvement and change.

Coping with Teasing

Teasing is a problem with three parts. Understanding these components are can help diffuse the process and avoid much of the emotional hurt teasing can bring.

1. Who is doing the teasing?
Is it someone close to you, or someone you hardly know? It is someone whose opinion matters, or someone you do not respect? These factors will have a great deal to do with whether the tease amused you or hurt your feelings.
2. Why did the teasing occur?
This is often difficult to discern, but it is important to consider whether the individual was simply uninformed and uncomfortable about his own feelings, or whether the tease was based in genuine dislike or jealousy.
3. Accept or reject?
After thinking about 1 and 2, decide the best course of action. If the teasing came from someone you do not respect or feel is important, ignoring it is the least waste of energy. If it is someone you care about, evaluating and clarifying the situation is worthwhile. Perhaps peer education will ease the problem

In every instance, encourage a sense of humour! Even the most difficult and embarrassing situation looks better through a smile.

"My face looks different. And sometimes people don't like me."

Lindsay, age 8

It can happen to anyone.

For those of us who do not have a facial disfigurement, it is difficult to imagine what it must be like. While we can appreciate the difficulties of looking 'different' in a society where beauty is so highly valued, we can never know all the painful feelings of isolation and rejection that people who are facially disfigured can suffer.

Facial disfigurement can happen to anyone, anywhere, at birth or later in life as a result of cancer, an auto accident, or fire. It could happen to someone you love - your child, your grandchild, your spouse, or yourself.

It could change your life.

> ***"I am a very optimistic person, but others can make you feel terrible. I don't consider myself disabled. But I know there are some people in society who do."***
>
> *Pierre, age 38*

Where would you go?

Founded in Canada in 1985, **AboutFace** is dedicated to providing individuals who are facially disfigured, and their families, with ongoing educational and emotional support. We are also committed to helping the professionals who care for them and the communities in which they live to understand their particular needs.

> ***"Within seconds, we could share things I had never told anyone else. That's what AboutFace means - letting people like me know that we're not alone."***
>
> *Lorna, age 28*

As well as chapters in Canada, **AboutFace** has established chapters in the United States, and our unique approach has also helped families and professionals world-wide, in countries as diverse as Poland, China, Australia, Kenya, India, England and Mexico.

What can we do?

- **AboutFace** li[illegible] helping people who are facially disfigured to accept themselves and confront the problems they encounter in their lives.

- **AboutFace** links people with similar concerns and experiences to help and support each other.

- **AboutFace** publishes a bi-monthly newsletter to promote public understanding of the issues and assist families seeking help.

- **AboutFace** brochures, information booklets and resource lists are used in clinics world-wide.

- **AboutFace** provides hospital visits for patients on a community level, and ongoing awareness programs for their health care givers.

- **AboutFace** believes that education is the key to understanding. We develop programs to encourage more positive social attitudes towards those who are facially disfigured. We also sponsor conferences and workshops to train individuals to develop support services within their own communities.

☐ **Yes! I want to support AboutFace with a donation:** ☐ $20 Membership ☐ $50 ☐ Other
☐ $25 ☐ $100

☐ Add my name to your mailing list. I'd like to become an active member and receive the bi-monthly newsletter.

Name ______________________________

Address ______________________________

City/Town ______________________________

Prov./State ______________________________

Country ____________________ Postal/Zip Code ____________________

Phone (Home) ____________________ (Business) ____________________

e make cheque or money order payable to: AboutFace 99 Crowns Lane 3rd Floor Toronto Ontario M5R 3P4
table Registration No. 0565077-11

For more information regarding our programs, publications and support services, or to obtain the number of your local AboutFace chapter contact:

AboutFace
99 Crowns Lane 3rd Floor
Toronto, Ontario Canada M5R 3P4
Tel: (416) 944-FACE Fax: (416) 944-2488

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Ronald McDonald Children's Charities of Canada.

Recyled Paper

AboutFace

Vol. 5, No. 6 November/December 1991

A support & information network concerned with facial disfigurement

U.S. Office of AboutFace

New Horizons

by Pamela Onyx, Director, U.S. Office

It is my great pleasure to announce the official opening of AboutFace's U.S. office in suburban Philadelphia, and to briefly describe the goals and services of the U.S. and International offices.

Networking will now be done through both offices, although the U.S. office will focus on advocacy as a primary goal. While those in Canada have national health insurance, we in the states do not. Insurance policies often fail to cover all the costs related to habilitation. Many revisional procedures are considered cosmetic and some orthodontic services, required to prepare the facial structures for further surgery, are classified as dental rather than medical services. The result of this is an accumulation of frustration and a need for families to be very assertive and tenacious in dealing with insurance carriers. Some states have passed legislation mandating coverage of all related treatment under the family's major medical plan, and AboutFace intends to work with consumers to introduce and sponsor legislation to this effect. If you are interested in this area or already have some expertise from your own state, please give me a call. We will also tap into the expertise of other established advocacy organizations, such as the American and National Cleft Palate Associations and the Association for the Care of Children's Health, to maximize our effectiveness. Within guidelines, lobbying is a legitimate activity for non-profits.

Our second target is to distribute AboutFace's excellent school program, "We All Have Different Faces". This program was developed to increase understanding and empathy to the needs of the facially disfigured student within the school community. An individual's school environment plays a prominent role in the socialization process, and AboutFace has adopted an advocacy role in educating fellow students and teaching staff about facial differences. Beginning with Philadelphia as a hub, we plan to move regionally through the U.S., offering training to families who wish to present the program in their local schools. Our needs for funding are many. We are in need of computer equipment (I'm currently borrowing my daughter's), a real office (we're now located in my home) and funds to cover programs and services. If you have contacts who could help us to meet some of these needs, please put them in touch with me. The U.S. office is in the process of applying for non-profit status (501(c)3) which will enable AboutFace chapters across the U.S. to also carry on fund raising activities for which contributions are tax deductible.

In the interest of efficiency, some programs will continue to be handled exclusively by the International office. Chapter Development, under the able leadership of Jane Richardson, is one such program. The newsletter is also produced there. As time goes on, literature, videos, and a resource library will become available through the U.S. office.

In this modern technological age, the two offices are able to stay in close communication with one another and confer regularly. It is this blending of all ideas, skills and talents which makes AboutFace a very special organization.

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Continued from page 1

You may wonder what brought me to this exciting opportunity. First and foremost, I am a mother. Our lovely 15 year old daughter Jennifer, was born with a cleft lip and palate. Shortly after her birth, I was introduced to three other mothers who had babies with clefts, a contact that was one of the most helpful and significant in my life. We all decided to form a support group for families with clefts in the Greater Philadephia area, which I am delighted to say continues to prosper today. Partly as a result of my involvement in this support group, I was hired as the Patient Educator/Coordinator of the Facial Reconstruction Centre at The Children's Hospital of Philadelphia. I stayed in that position for seven years during which time I helped to form the AboutFace Philadelphia chapter for craniofacial families. I also became involved in the National Cleft Palate Association of which I am the immediate Past-President. I am thrilled and honoured to have this new position, and I will do my best to provide you with quality service.

AboutFace U.S. Office
1002 Liberty Lane
Warrington, PA 18976
Tel: 1-800-AB5-FACE
(215) 491-0602
Fax: (215) 491-0603

Notes from Crowns Lane

by Elisabeth Bednar, Executive Director

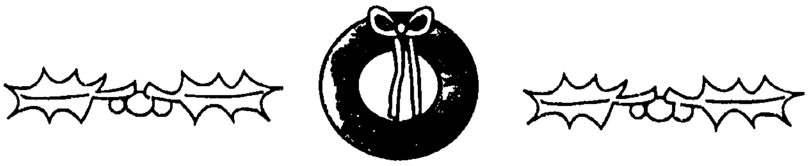
We are just delighted to be announcing the opening of our Amercian office in this issue. Pam Onyx is a great asset to our organization and all of us are looking forward to working with her as she takes on this challenging position.

The list of communities interested in AboutFace continues to grow and through the Chapter Development Program we are able to help individuals work towards having a local support group. Ongoing telephone support and training workshops provided by our International Office offers help with the initial phases of development, and what may have seemed overwhelming becomes much simpler with clear guidelines.

In working with families and individuals in these groups, Jane and I continue to marvel at the blend of ages and concerns - how such a mix enriches the experience for all involved. As Diane Breton describes in her article this month, what an affected adult can share with a parent somehow gives special meaning to the challenges they have overcome. As well the mix of various conditions - whether cleft lip and palate or Moebius syndrome, we find the stories we share all have a common thread. We feel this blending of individuals with different disfigurements reflects the move across the country to have ALL disabilities work more closely, rather than singling each subgroup out for their specific diagnosis. In other words, focusing on our similarities, not our differences.

Holiday seasons in the past, I have written about the smells of Christmas wafting from my kitchen. This year, these will doubtless be initiated by my children, as they develop their cooking skills to help with our crazy schedule. I don't know why, but I think there is something more delicious about lop-sided meatloaf or crumbly butter tarts when they are made with such love.

All the best to you and yours!



Readership Survey Results

Thanks to everyone who took the time to answer our readership survey (which was enclosed in the last newsletter). We were delighted to see that over 65% of those who responded read almost all of the newsletter, followed by people who read over half (30%).

Here's what you had to say was most interesting:

- 65% - personal stories
- 20% - articles on parenting issues
- 10% - articles on hospitalization issues
- 5% - resources and reading suggestions

News from the international office and local chapters was not as popular - readers found these topics slightly interesting (31% and 30% respectively). The overall opinion of the newsletter was good (50%) or excellent (34%). The appearance and content were rated as good (39% and 41%) or excellent (39% and 27%). One third of you said the ease of reading and writing style were good; one third responded with excellent.

As a result, we will be modifying the newsletter format. In future, efforts will be made to include personal articles more often. In the new year, page 3 will feature a different syndrome, accompanied by relevant resources/reading suggestions.

The interests expressed covered a wide range of issues, and we appreciate your comments. We will keep working to make this newsletter reflective of the issues that concern you! Again, thank you for your comments.

AboutFace

Chapters and Contacts
CANADA

Alberta

Marg Sletten, Contact Person
c/o Alberta Children's Hospital
Cleft Lip and Palate Clinic
1820 Richmond Rd. SW
Calgary, Alberta
T2T 5C7
Tel: (403) 229-7308

Patricia Janz, Contact Person
2025 25th St. SW
Calgary, Alberta
T3E 1X1
Tel: (403) 240-2459

Nerissa Thomas, Contact Person
Cleft Lip and Palate Clinic
University of Alberta Hospitals
8440 - 112 St.
Edmonton, Alberta
T6G 2B7
Tel: (403) 492-8822

British Columbia

Donna Duke, Contact Person
211 - 315 Primrose Road
Kelowna, B.C.
V1X 2G6
Tel: (604) 765-6034

Elaine Abramson, Treasurer
Vancouver Chapter
10446 - 125A St.
Surrey, British Columbia
V3V 4Z9
Tel: (604) 589-0619

Manitoba

Lori Jacquie Cosens, Contact Person
Box 62A
Marquette, MB
R0H 0V0
Tel: (204) 353-2531

Ontario

Jane Richardson, Chp. Coordinator
Hamilton Chapter
37 Brookfield Blvd
Dunnville, Ontario
N1A 3G2
Tel: (416) 774-2552

Jean Cousins, Coordinator
London Chapter
1132 Adelaide St., Apt. 503
London, Ontario
N5Y 2N8
Tel: (519) 433-9066

Donna Montague, Coordinator
London Chapter
RR8
London, Ontario
N6A 4C3
Tel: (519) 451-1137

Anne Charbonneau, Coordinator
Ottawa Chapter
6064 Jardin des Treflieres
Gloucester, Ontario
K1C 5I9
Tel: (613) 592-5910

Sharon McInnis, Coordinator
Ottawa Chapter
1217 Willowdale Ave.
Ottawa, Ontario
K1H 7S5
Tel: (613) 521-4024

Mary Gabriele, Chapter Coordinator
Toronto Chapter
68 Squire Graham Lane
Woodbridge, Ontario
L4L 7C5
Tel: (416) 856-2737

Kathy Cressey, Contact Person
54 Victoria St.
Port Colborne, Ontario
L3K 2Y2
Tel: (416) 835-2818

Rose Mousaly, Chapter Coordinator
Windsor/Essex Chapter
9420 Ridge Road
Windsor, Ontario
N8R 1G4
Tel: (519) 735-5810

Québec

Pierre Manseau, Chp. Coordinator
Montréal Chapter (Envisage)
4346 Girouard Avenue
Montréal, Québec
H4A 3E4
Tel: (514) 486-7831

Maritimes

Anne Lavalette, Contact Person
21 Silverside Dr.
P.O. Box 49, R.R. 1, Site 8
Waverly, Nova Scotia
B0N 2S0
Tel: (902) 860-0389

International Office
99 Crowns Lane 3rd Floor
Toronto Ontario
CANADA
M5R 3P4
Tel: (416) 944-FACE
FAX: (416) 944-2488

U.S. Office
1002 Liberty Lane
Warrington PA 18976
U.S.A.
Tel: 1-800-AB5-FACE
(215) 491-0602
FAX: (215) 491-0603

AboutFace

Chapters and Contacts

U.S.A.

California

Sandy Goodwick, Chp. Coordinator
Glendale Chapter
320 E. Stocker St., #301
Glendale, California 91207
Tel: (818) 548-1822

Noreen Clark-Sheehan, Contact
Los Angeles Children's Hospital
Division of Plastic Surgery
4650 Sunset Blvd.
Los Angeles, California 90026
Tel: (213) 669-4543

Conneticut

Rita Brzozowski, Contact Person
190 Tomlinson Ave., Unit 12D
Plainsville, Conneticut 06062
Tel: (203) 793-1065

Florida

Amy Horowitz, Chapter Coordinator
Florida Chapter
9519 S.W. 118 Court
Miami, Florida 33186
Tel: (305) 279-5941

Nancy Jacobson, Contact Person
4083 Sunbeam, Apt. 2217
Jacksonville, Florida 32257
Tel: (904) 636-0517

Illinois

Laurel Barbour, Contact Person
Michael Reese Hospital
2800 Ellis
Chicago, Illinois 60616
Tel: (312) 808-4700

Missouri

Mark Renken, Chapter Coordinator
St. Louis Chapter
10 Cedar View Court
St. Charles, Missouri 63303
Tel: (314) 946-4811

New York

Susan Gillick, Coordinator or
Marcia Kester, Coordinator
Tel: (716) 668-4730
Buffalo Chapter
67 Highland Ave.
Buffalo, New York 14222
Tel: (716) 881-5930

Diane Breton, Contact Person
88 Kenmore Lane
Rochester, New York 14617
Tel: (716) 467-2182

North Carolina

Ruth Tansill, Contact Person
5514 Murrayhill Rd.
Charlotte, North Carolina 28210
Tel: (704) 376-4735

Oregon

Susan Thompson, Chp. Coordinator
Oregon Chapter
5233 N. Emerson Drive
Portland, Oregon 97217
Tel: (503) 283-1339

Pennsylvania

Diana Sweeney, Contact Person
c/o Facial Reconstruction Centre
Children's Hospital of Philadelphia
First Floor, One Children's Centre
34th & Civic Centre Blvd.
Philadelphia, Pennsylvania 19104
Tel: (215) 590-2214

Texas

Judy Nicolson, Contact Person
1427 Bayshore
Kemah, Texas 77565
Tel: (713) 929-6118

Utah

Brenda Christensen, Contact Person
4826 Quail Pt. Road
Salt Lake City, Utah 84124
Tel: (801) 277-9902

Wisconsin

Elisabeth Knaack, Chp. Coordinator
Wisconsin Chapter
5163 N. 107th St.
Milwaukee, Wisconsin 53225
Tel: (414) 466-4534

International Office
99 Crowns Lane 3rd Floor
Toronto Ontario
CANADA
M5R 3P4
Tel: (416) 944-FACE
FAX: (416) 944-2488

U.S. Office
1002 Liberty Lane
Warrington PA 18976
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(215) 491-0602
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AboutFace helps . . .

Across the miles

by Diane Breton

I am an adult with Moebius Syndrome. I want to tell you about July 5, 1991 when two adults and three children with the same rare syndrome shared a wonderful afternoon. Moebius (or Mobius) Syndrome is a very rare congenital facial and eye muscle paralysis which may occur with various other muscle/bone problems. Some estimates in the literature report that only about 700 people in the world may be alive with it at any one time. To have five people with this same syndrome in the same place, at the same time is surely a first.

Networking through AboutFace played a major role in helping this meeting happen. Sandy Goodwick, an adult with Moebius from Los Angeles, was looking for a way to talk with others with the same syndrome. She called across the continent to AboutFace in Toronto and found people there who were familiar with the name Moebius. What a lift to have the syndrome recognized instead of having to start from scratch explaining what it is!

They put Sandy in touch with me. After we talked for a couple hours by telephone I arranged to fly to Los Angeles for the July 4th weekend. It was a beautiful experience to have two strangers trust and help each other!

Then Sandy tapped AboutFace again to find other families in the area to meet with us. Many themes weaved through our conversations that day. Parents spoke of their struggles when they learned their child had Moebius Syndrome and they were unable to receive helpful or accurate information. They wanted to know about problems we as adults had growing up, and we were interested in how the children were coping right now. Anger was expressed at being alone as parent, child and adult to deal with such a rare condition. Sandy and I grew up without knowing anyone else who was facially different, and it was rewarding to be able to offer support to children in the hope that they will not feel so alone. Relief and happiness were felt when problems were shared. We watched a video of "Mirror Mirror", a CBC Man Alive program which features members of AboutFace. Although Moebius Syndrome in particular was not discussed on this program. I am sure others in AboutFace have learned, as we have, that there are many feelings and experiences common to all those who have a facial disfigurement. We all agreed that everyone would benefit from seeing it, not just people affected by facial disfigurement.

Left to right: Sandy Goodwick, Diane Breton, Chelsey Thomas, Ted Simpson and Allan Marshall with his mother Linda. Not pictured but present were Lori Thomas and Phillip and Liz Simpson.

Our afternoon ended with a discussion about how to get a local chapter of AboutFace started there. The movement is growing and the effects are appreciated over and over again.

• • • • • • • • • • • • • • • • • •

Suggested Reading

Kumar, D. Syndrome of the Month: Mobius Syndrome. *Journal of Medical Genetics.* 1990; 27: 122-126.

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AboutFace newsletter is supported by the Trillium Foundation and the Toronto Chapter of the Canadian Hotel Marketing and Sales Executives

Dates to Remember

√ **February 6 -7, 1992**
ABOUTFACE SUPPORT TRAINING WORKSHOP
For information please contact:
Barbara MacKenzie
BC Children's Hospital
Tel: (604) 875-2345 ext. 7057

√ **December 6, 1991**
DEADLINE
for submissions to the January/February 1992 issue of the AboutFace newsletter

• • • • • • • • • • •

I am only one,
But I am one.
I can't do everything
But I can do something.
What I can do,
I ought to do,
And what I ought to do,
I will do.

Anonymous

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Canada M5R 3P4
Tel: (416) 944-FACE
FAX: (416) 944-2488
Editor: L. Renooy

Articles may be reprinted in whole or in part with acknowledgment given to AboutFace as the source.

Articles and ideas are welcome!

Gifts for sharing

TRIBUTE CARDS

For all occasions, these cards come packaged in groups of five for $25.00 (including mailing envelopes) with full donation receipt.

Available from the AboutFace International Office.

Rosey . . .
the imperfect angel

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 even a little different. It is a tale told with real love that holds the promise of a happy ending.

Available from the AboutFace International Office. Price is $20.00 (CDN) which includes postage and handling and donation to AboutFace.

Gifts for Daily Giving

- *Hug someone every day.*
- *"Feature" a family member's favourite dinner once a month.*
- *Contact an old friend and tell them how much you care.*
- *Play a game with your children - their choice.*
- *Really listen when you ask "How are you?"*
- *Extend a warm smile to someone who needs it.*
- *Walk in someone else's shoes.*
- *Tell someone they did a terrific job.*
- *Plan a surprise evening with your "significant other".*
- *Write a friend.*
- *Hold someone's hand.*

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AboutFace

Vol. 6, No. 1 January/February 1992

A support & information network concerned with facial disfigurement

Face Up to It!

Flashlamp pulsed dye lasers make a real difference

by Fiona Brown

After four trips to the laser clinic I feel really comfortable being "under the gun". I know where to park, I know where to get a cup of coffee, and I know that the doctor will do a good job. She talks to me during the treatment and that goes a long way to blocking out what I think of as pain, but which most people would describe as "moderate discomfort".

After four treatments I have a rapidly fading port-wine birthmark on my left cheek. I am delighted by this new laser technology. When I was 16, and in the throes of adolescent self consciousness, I made one visit to a plastic surgeon, but the predictions that "it could be better, but it could be worse . . . "had convinced me not to interfere with my natural good looks. When I first heard of the flashlamp pulsed dye laser process my interest was revived. A non-invasive treatment which boasted impressive results seemed attractive. The news that it was covered by OHIP was even more attractive!

Each treatment takes about fifteen minutes and consists of 150 "zaps" with then pen like laser. A "zap" feels as if I've been stung by an elastic band, and the areas below my eye and above my top lip are the least fun! Nobody knows how many treatments I'll need, it could be five to ten depending on the number of discoloured layers. The worst part is the first three days after the treatment because my cheek erupts into a swollen bruise, partially closing my left eye. The skin turns almost black. I have to coat it with an antibiotic gel, and wear a huge band-aid. The good news is that the discomfort fades within an hour of the treatment and the swelling and discoloration lessen noticeably by the hour. It's all a small price to pay for the improvements so far.

When I first told my family in Canada about the treatment, they were genuinely worried. They really thought that it would change me, that I might lose my outgoing personality. I thought that was a crazy idea, and so far I believe that any changes have been for the better. "Yes", the birthmark is something that I've always had, and "no" it hasn't stood in my way. My friends - on the rare occasions that I've mentioned it - all say pretty much the same thing, "Well, I noticed it when it first met you, but I don't even see it now."

So why bother? I'm not sure. At 32 years of age I'm very comfortable with the person that I am. If I had to explain my decision I think the single biggest reason is because I want to see the look on my mother's face when I next go home to England. She doesn't know about the treatments. We have only discussed my birthmark once, about four years ago, and she seemed sad. When I was born the doctors told her that it wasn't her fault, but somehow I think she has always believed that it was.

> ***"A non-invasive treatment which boasted impressive results seemed attractive"***

As an adult it is great to be able to access this treatment, particularly for people who have more extensive marks which really do affect their social experiences. I think the greatest advantage is for children. Childhood and adolescence are especially tough for people who look visibly different. I remember many incidents of name calling and pointing that I would prefer to forget. A few tears over treatment seem an attractive alternative to a decade of adjustment.

If you have a child with a port-wine stain, please explore the flashlamp pulsed dye laser options. This is a priceless and relatively painless piece of technology that is available to all of you.

Fiona Brown is a professional fundraiser with the Easter Seal Society. Easter Seals provides special equipment and services to children with disabilities.

Another chapter in Canadian history . . .

A Capital Idea!

Ottawa would like to make an announcement. We now have an AboutFace Chapter in our area. Members of the Executive are:

Anne Charbonneau - Coordinator
Sharon McInnis - Coordinator
Micheline York - Chair, Patient/Family Services.

For more information, please call: Anne Charbonneau
Tel: (613) 837-7154 or
Sharon McInnis
Tel: (613) 521-4024

Notes from Crowns Lane

by Elisabeth Bednar, Executive Director

Happy New Year - 1992 brings changes with a new face in our office. Alex Asante has joined us to help with administration and accounting. From Ghana, Alex brings not only help with programs and financial matters, but great enthusiasm for Canada.

Our members are frequently the recipients of special recognition, and we are delighted to congratulate them. On page 4, we feature Leslie Richardson's speech which won second prize in her school's public speaking contest. Leslie, in Grade Four, competed against the senior grades in her school. After reading her story, you'll know why she placed so highly! Leslie is the eldest daughter of Jane and Mark Richardson (Jane is our Chapter Development Coordinator).

Kudos also go to Khrista Boylan from Halifax, Nova Scotia, who was one of the 36 students in Canada chosen from 860 applicants to receive the Terry Fox Humanitarian Award. This award is given to individuals who maintain high standards in extra-curricular, voluntary, social, athletic or academic endeavours, while exemplifying the fighting spirit of Terry Fox in overcoming obstacles in their lives. Khrista, who sparkles as one of the stars in our school video, "The Beauty Within", will receive $4000 yearly towards her first university degree.

Twelve year old Kimberley Wright's achievements have been featured before in our newsletters. Last June, Kim received first prize for academic work in Grade Seven at the Cayman Preparatory School, as well as third prize in her age group in the Royal Commonwealth Essay Society. Kim lives on Grand Cayman Island with her parents Grace and Ken Wright.

News from the U.S. office is exciting - we are now federally incorporated in the United States. Pam is working overtime to fund-raise, establishing a base on which to expand. Our U.S. mailing this issue includes a letter asking for your help. We look forward to hearing from you!

Putting Your

Best Face Forward

By Heather Bland

It was not easy growing up and looking different from the other children. It's always there, face first. Make a good first impression, isn't that the old saying? I think I started wearing some form of cover-up make-up at the age of six, probably when I started school. I have been diagnosed as having a congenital venous malformation. It affects my left cheek and upper lip and I have had numerous surgeries to try and correct this.

My mom was wonderful! She was very positive and upbeat to me about the difficulties I experienced. She told me that my appearance would only be a problem if I let it, so I decided quite early in life that it wouldn't. I believe the problems we face will make us stronger if we don't allow ourselves to become bitter. I think we have to accept the fact that people are curious about anything or anyone out of the ordinary. Explaining the problem quickly and unemotionally usually gets it out of the way. After awhile, you'll get very good at this!

Still, I continued to wear only a cover-up make-up and did my hair in a certain way to conceal as much of that side of my face as possible. I refused to wear any colour such as lipstick or eyeshadow, believing it would draw even more attention to my face.

While employed as a secretary I was given the opportunity of becoming a Mary Kay Beauty Consultant. I realized how helpful it was learning how to apply make-up correctly and the difference it made in the way I felt about myself. What a relief to see a marked improvement when my eyes were made the focus of my face instead of my cheek. Learning how to contour and shape my cheeks really helped! And even if I was missing part of my lip, I could correct this with a lip pencil. After ten years in this line of work I've realized a couple of things. First, *most* people are self-conscious about some aspect of their facial appearance! Second, putting your best self forward allows you an increased self-confidence, so spend a little extra time to make yourself look the best you can, then forget it and get on with your life. There are lots of wonderful people out there who *will* bother to look beneath the surface. As my husband said to my mother when she asked if my face bothered him, "I never got past her eyes!"

Port-wine Stain

by Trudy Baird, RN

The port-wine stain, medically known as naevus flammeus, is a vascular birthmark which persists throughout life and has an incidence of 0.3-0.5 per 1,000 births. It is characterized by a pink to purple color located anywhere on the skin, but occurring most often on the face. One such example is the birthmark on the forehead of Soviet President Mikhail Gorbachev.

These lesions may be either isolated or associated with other structural abnormalities underlying the birthmark. Such examples involve the vessels in the eye which may cause glaucoma, or central nervous system involvement which may result in seizure activity.

Early treatment of port-wine stains has a direct advantage in the prevention of psychological trauma in affected children and families. Early treatment also prevents the progression of vessels which are classically faint pink in children, to red-purple and often hypertrophic (raised) once the person reaches adulthood. This is a common complication of extensive port-wine stains by middle age.

Over the past decades many treatments such as surgery, x-ray therapy, cryosurgery and cosmetic camouflage have been attempted with limited success. The argon laser emerged in 1972 as the first major advance in therapy for port-wine stains. The argon laser treatment used a high intensity blue green beam which passes through the skin's surface and is absorbed by the target oxyhemoglobin. It's effect is to coagulate and seal blood vessels thereby eradicating the red lesion. This treatment provides good to excellent clearing in about 80 percent of adult patients with report of hypertrophic scarring in fewer than 5 percent, although altered skin markings are common.

Unfortunately argon laser therapy produced cosmetically unacceptable scars in 5 percent of children. Some centres using the recently developed pulse tunable dye laser give early reports of moderate to excellent clearing results. Additional treatments over several years, as well as post operative wound care, and prevention of infection are essential for the ongoing process needed in the eradication of this lesion.

Although port-wine stains are considered a cosmetic problem, more importantly it is a condition with potential physical and psychological complications. The extraordinary social stigma of a "marked" person requires the laser surgeon to continue to evaluate the ongoing treatment and to be sympathetic to the emotional needs of the affected person.

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References

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Now Available . . .

"We All Have Different Faces"

A school education program developed to increase understanding and empathy within the school community to the needs of the student who has a facial disfigurement.

"Beyond Face Value"

This 20 minute video features young people who have a facial differenc4e discussing their concerns and experiences.

To obtain copies, please ontact AboutFace.

"We All Have Different Faces"	**$ 7.00**
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The second printing of "We All Have Different Faces" was made possible through the generous financial support of
The Trillium Foundation
Ronald McDonald Children's Charities of Canada
Sir Joseph Flavelle Foundation

The AboutFace newsletter is supported by the Trillium Foundation and the Toronto Chapter of the Canadian Hotel Marketing and Sales Executives

Dates to Remember

✔ **February 6 - 7, 1992**
ABOUTFACE SUPPORT TRAINING WORKSHOP
For information please contact:
Barbara MacKenzie
BC Children's Hospital
Tel: (604) 875-2345 ext. 7057

✔ **May 12 - 15, 1992**
ACPA Annual Meeting
NCPA Annual Meeting (May 15)
Portland, Oregon
For information please contact:
Tel: (412) 481-1376

✔ **February 20 -21, 1992**
Thirteenth Annual Symposium on Ped. Hematology/Oncology
Columbia South Carolina
Theme is psychosocial care with emphasis on support groups and therapeutic techniques for children and families.
Contact: Rosemarie Krautler
Children's Centre for Cancer and Blood Disorders of Richland Memorial Hospital
Tel: (803) 765-6484

✔ **February 7, 1991**
DEADLINE
for submissions to the March/April 1992 issue of the AboutFace newsletter.
Topic: Hemi-Facial Microsomia.

My Sister Lauren

by Leslie Richardson, age 10

Have you ever heard of a country called El Salvador? I have, because my sister Lauren was born there. El Salvador is a very small country in Central America. A lot of wars take place there, and it is very poor. El Salvador is famous for growing coffee and for brightly painted crafts. Our family collects these crafts. Wherever we go we always look for them, and buy them to add our collection.

Lauren was born with a cleft lip and palate which is a hole in the lip and in the roof of her mouth. Our family adopted her when she was three months old. When she arrived she was very sick, because in El Salvador they don't have proper medicine. When she gained weight she had her first operation - she had her lip closed. Lauren has had six other operations and she has a lot more to come. Although Lauren has had all these things happen to her, she is just the same as you and me.

Lauren's favourite things to do are: playing outside, playing with the cars, helping Dad make a fire, reading stories - she even likes washing the dishes!!!!!! Lauren's favourite movies are the "Little Mermaid" and "The Land Before Time".

We have a book of pictures from her operations, and when anybody comes over she shows it to them. Lauren calls that book her operation book. When we go on an elevator, Lauren tells people she does not *even know* all about her operations. Boy is that embarrassing! One day last summer we went to a family picnic in Kingston. There we met a lot of children that were adopted from El Salvador too.

In Central America there were an ancient people called the Mayans. They were really smart, and could build all kinds of buildings without the tools we have today. We do not know much about Lauren's birth parents. Sometimes when I look at her, I wonder if they might have been really famous.

Maybe Lauren's great great Grandpa was a brave Mayan leader. Maybe her great great Grandma was a beautiful Queen from Spain. This is something we will never ever know, but it sure is fun to think about. Someday if the war in El Salvador is over, our family might take a trip there so that Lauren could see where she was born.

Maybe some of you have a brother or sister adopted from a foreign country too. If you do, I hope they are as much fun as my sister Lauren, and I hope that you love them, as much as I love her.

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Canada M5R 3P4
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For parents, teachers and young adults

Association for the Care of Children's Health.
ACCH is a non-profit organization whose members - health care professionals, educators, researchers, and parents - share a commitment in responding to the unique emotional and developmental needs of children. A wide variety of excellent resources are available. (7910 Woodmont Ave., Ste. 300, Bethesda, MD 20814).

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