

# Neurosurgery

## PARENT SUPPORT GROUP Newsletter

VOLUME 1

SUMMER 1983

NUMBER 1

### Start Now | Get Involved

The first meeting of the PARENT SUPPORT GROUP was held in May and provided an excellent opportunity to discuss common concerns, problems and possibilities facing parents of children with shunts. The following goals were proposed:

- 1. Obtaining medical coverage for children over 18 years.
  - 2. Providing parent/child education through presentations and materials.
  - 3. Establishing a sibling and teen support group.
  - 4. Helping each other to identify and develop solutions to the problems of living with a child with Hydrocephalus.
- If you are interested in becoming a member or contributing in any way, please complete the tear-off portion on the reverse side of this newsletter.

### Readers' Exchange

#### VACATION TIPS

If you are going on a vacation and have some concerns about your child's health while you are gone, here are some suggestions:

1. Check with your doctor about a physician in your vacation area.
2. Request a letter from your child's physician regarding his/her condition.
3. Be sure you have your insurance/Medi-Cal card with you.
4. When you reach your destination determine where the local hospital is.

Let's hope you never need to make use of these suggestions, but it is helpful to be prepared.

HAPPY, HEALTHY HOLIDAYS!!!!!!

Robert and Brenda Lloyd of Visalia tell us if your child is less than 18 years and needs a wheelchair, one can be obtained by calling the Shriner's Organization and completing an application.

#### BLOOD TRANSFUSIONS

Children with Hydrocephalus and shunts rarely require transfusions even though they may have surgery numerous times. This fact has been confirmed by Dr. Michael Edwards, Neurosurgeon at U.C. Moffitt Hospital. In the unusual event a transfusion is required for your child, what can you do to insure that the needed blood is as disease free as possible?

The Irwin Memorial Blood Bank, which supplies blood for Moffitt Hospital, assures us their blood is thoroughly tested and free of infectious material. They screen their donors very closely and test all blood completely. It is possible to set up a group donor account whereby a minimum of 15 people donate blood as a group, providing for this group 15 free pints of blood for any member (or family of member) for a period of one year-to be continued each year with an additional donation of 15 pints of blood per group. However, there is no way to organize this program whereby the 15 pints of blood donated are the same 15 pints available to the group. Blood life is 35 days and no provisions are available for the group account to insure the group members receive only their blood. A group account such as this would provide the members with blood free of charge and the comfort that the members were supporting one another through this plan.

It is also possible, if blood types match, for a parent with a child at Moffitt to donate blood for their own child. We are attempting to obtain more information on how this procedure works. It is important for all of us to know our own blood type and that of our child and to keep this information handy in case of emergency.

---Emily Fudge

"Oh, I can't go to school; my hair looks awful!" "I can't let anyone see my nails because I broke some of them." "My mom will kill me for getting an "F" on that test." "I can't let anyone see my face, because it has too many pimples." "Everyone will laugh at me because I have to sing a song in front of the class." "I didn't win that race because I tripped and fell."

How important are these things? Some people don't have hands on which to grow fingernails, some people don't have any hair, some people don't have any legs, with which to run races, and some people don't have any voices with which to sing songs. We take all of these things for granted! But, because of my illness, I have learned that we cannot. The greatest gift is to be healthy.

My experiences in the hospital have helped me to understand that many people are sicker than I am and that I should enjoy each day as it comes. Being able to appreciate good health and good qualities in people is another thing I have learned. Chronic illness in myself and others has made me more aware of how valuable good health really is.

There are two different kinds of illness: chronic and acute. A chronic illness is an illness from which one is never free. Some examples of chronic illnesses are: diabetes, kidney disease, cystic fibrosis, epilepsy, asthma, heart disease and hydrocephalus. An acute illness is a disease or infection that strikes suddenly, but can be cured most of the time. Some examples of an acute illness are: peritonitis, meningitis, hepatitis, mumps, measles, chicken pox and influenza.

Children who grow up with a chronic illness seem to be more understanding of other people's differences than healthy children, who have never been exposed to handicaps. They can accept children who look different because of missing hair, missing arms or legs, scars, strange looking equipment or retardation. Each of these children has so many good qualities that we learn to overlook his or her handicaps. I have never seen so much kindness, caring, and love as I have among hospitalized children.

I don't notice how good it feels to be healthy and out of the hospital. I always just take it for granted. For instance, when I'm healthy and active I never notice how good it feels until I cannot do my regular activities because of illness. I am used to using two hands and arms with which to eat, play, and do schoolwork. When I have an IV tube in my arm, I can't do these things well. But I am one of the lucky ones for when I get it out I can once again ski, swim, go to school and lead a normal life. Some children cannot.

Sunsets are like people. We enjoy each sunset for itself. They are all different. In a sunset, we never try to add a little orange here, a little red there and a little purple. In the same manner we can appreciate people being different just as we appreciate different sunsets. We enjoy each sunset as it happens. We need to learn to enjoy people the same way.

Jill is a teenager with Neurofibromatosis and requires a shunt. The above is a speech written for her English class.

THAT A CHILD  
SHOULD GROW.

