VOLUME 14-1

Spring/Summer, 1996

INSURANCE NOTE

Details

Written by Tish Fuller

Published: 17 July 2009

For those who have insurance, you may be interested to know that Walgreen's Healthcare Plus now carries MSUD Diet Powder and MSUD 2 by Mead Johnson. This arrangement with Walgreen is through insurance companies only; it is not available for uninsured individuals to purchase.

To purchase formula through Walgreen Healthcare Plus, you must have a doctor's prescription, which is mailed to Walgreen's distribution center in Florida. This prescription is to cover approximately four months at a time, and is to be refilled approximately three times per year. You will receive large shipments of formula, so ensure that you have space to store it. These shipments arrive by UPS. Refills can be made by calling a 1-800 number. For any questions, please contact Walgreen's Healthcare Plus at 1-800-999-2655.

AN OBSERVATION

Details

Written by Joyce Brubacher

Published: 17 July 2009

Katie Fox wrote this winter about an experience of her daughter, Ruth, age 8. Getting too cold seemed to make Ruth listless and tired. The doctor thought maybe her leucine levels were plenty low during the previous summer and fall, depleting her protein. Then the cold

made her muscles contract causing her to stagger and feel weak.

After they increased her formula and added more leucine, she did better the rest of the winter. Has anyone had a similar experience?

SKILLS FOR INDEPENDENCE

Details

Written by Anne Fredericks

Published: 17 July 2009

Anne Fredericks told me about the unique school program that has helped their son, Jeff. I am pleased she is sharing this experience. We all need encouragement to help our children reach their full potential. We printed Anne's original history of Jeff in our second Newsletter way back in '83. Greg, Ann and son, Jeff live in State College, Pennsylvania.

I wanted to update our friends in the MSUD family about the accomplishments of Jeff Fredericks. For those of you who don't know or remember Jeff, he was diagnosed very late (16 months) and had quite a lot of neurological damage. But since he has a small amount of enzyme, he is considered a variant, and has accomplished a great deal, despite the delayed start.

Jeff is now 21 years old and is going to finish high school this year. Jeff has been in Learning Support classes all of his life. The high school class has been called "The Wild Dream Team." Two years before Jeff started in the class, the students decided that they wanted to take a trip. The teacher asked them to dream. . . "Where in the U.S. would they like to go?" They decided on Disney World. To get there, they asked people to donate frequent flyer miles and money. And they got there!

The next year, their teacher wanted them to give back to the community. So they entered the Good Housekeeping/Paul Newman cooking contest, in which they were finalists. They went to New York City to have lunch with Paul Newman and collect their $10,000 prize. With this money (and some additional community money) they bought a handicap accessible van for Easter Seals. When Jeff got in the class, they won another contest and went to New York. They gave $5,000 to Easter Seals this time. Then it was time for another "Wild Dream" vacation, and they went to Arizona to the Grand Canyon and a Dude Ranch. We are very proud of this group because they set goals, and they surpass them.

But the latest venture has really been incredible. The students came up with an idea that the school district would fund an apartment where these high school students could rotate time for 1 to 2 week stays, so they could really learn to be independent. Well, it has come to be - it is called the Life Link Lab. And Jeff has matured so much at the apartment. There are transition coaches who stay there to help with shopping, meal preparation, budget, chores, and any crisis that arises.

Just before the apartment program started, we attended the Symposium in Missouri. We

were especially inspired by the person in Washington State who runs nutrition classes for metabolic diseases at their clinic. We admitted that Jeff (at 19 years) did very little for himself - he refused to make his MSUD formula or do any cooking. When we learned that much smaller children could do those tasks, we vowed to go home and get Jeff to take over these essential life skills. We found a graduate student from Penn State University who started to help Jeff.

Jeff learned to measure using various dry ingredients. Next he learned to pour a package of formula (pre-measured by his parents) into the blender. Then he independently made his own drink. He also adds some extra amino acids and crushes his own pills to add to the drink. This was a big step for him and he is very proud of his accomplishments.

Since he leaves home to live at an apartment for a week or more, he has had to learn to do some basic cooking. He still has a long way to go, but we now feel that he can live on his own with minimal assistance.

SHARING - THE GAUVIN FAMILY

Details

Written by Joyce Brubacher

Published: 17 July 2009

Jeannine Gauvin is the mother of three teenage boys. Two of them have MSUD. What a challenge! She sent a picture at Christmas and mentioned I could use it for the Newsletter. Since families are interested in how the older children are doing, I asked Jeannine to write a brief account to go with the picture. When I did not receive one, I called her and learned she recently had an acute, severe attack of iritis which caused her to suddenly go blind. Eight weeks later she was recuperating and had some sight back. Doctors are still not sure of the cause.

She told me Allen and Jason are doing fine just now. The boys have classic MSUD. Allen was diagnosed at 9 days of age and hospitalized, but was not started on formula until 3 weeks old. Jason was diagnosed by amniocentesis and began the diet at birth. Both boys have been similar in their growth and development. Both had numerous hospitalizations doing the first several years of life but these decreased significantly as they grew older. Infections affected the boys differently. Allen would became lethargic whereas Jason tended to be hyperactive, neurotic and develop seizures. Jeannine monitored their diets very closely, and they maintained levels of 200 to 300 µm (2.5 to 4 mg./dl) when they were younger. The boys are very disciplined in their diets and now make their own formulas. Although responsible for their diets, they need some reminders from Mom from time to time.

The boys lift weights and have been very active in sports. Jeannie notices Jason and Allen do tire more easily than her older son. She also found puberty has an effect on their amino acid levels.

Growth spurts and physical changes add stress which influences levels beyond dietary control.

Speech and language are weak areas and both had some special help in school. Dale is enrolling in college for this fall whereas Allen and Jason's doctor advises vocational training for them. They are outgoing, active, sociable boys with a supportive brother, loving, dedicated mother and caring father. We wish them well.

FEATURED FAMILY - BRITTANY FULLER

Details

Written by Tish Fuller

Published: 17 July 2009

Tish first wrote about Brittany for our June '89 issue of the Newsletter. Brittany had been doing well, and Tish wrote at that time with a concern that families get the "whole picture" and not just the bad experiences. This update proves again that children with MSUD can do very well, in spite of an occasional bad experience, when they have been detected early and maintain good dietary control.

Brittany was born September 24, 1987 in Baltimore, MD. She was our first baby, and my mother was convinced that she was the most beautiful baby ever born, especially in the Seiwert family. Of course Mike and I readily agreed with her. Brittany weighed 7 pounds, 1 ounce, and was 19, inches long. All her initial hospital tests, including the Newborn Screening, came back negative. I began nursing her in the hospital and didn't seem to have any problems. For some reason, which to this day I will never understand but will bless her for the rest of her life, our pediatrician said she wanted us to stop by her office when Brittany was 4 days old. She wanted to do another Newborn Screening test.

I began having problems nursing Brittany when she was about 5 days old. She would nurse for a couple of minutes, then fall asleep. I was concerned she wasn't getting enough to eat. The pediatrician said to keep trying and not to give up. The pediatrician didn't seem concerned, so I continued trying to nurse.

During this period, Brittany was really not very difficult at all. There were some fussy periods, but nothing that seemed very unusual for a baby. I do remember how utterly sweet she smelled. But with the different baby products available these days, babies do tend to smell good. I was, however, becoming more and more concerned about the small amounts of milk Brittany was getting. Something just seemed to be wrong. And, unfortunately, we had no relatives close to whom we could go with our questions.

When Brittany was 11 days old, I called the pediatrician and asked her what formula to use, as I was planning to quit nursing her. That day, Brittany took the bottle exceptionally well. I

felt MUCH better. However, the following morning, the pediatrician called to say that Brittany's Newborn Screening test showed a positive result. Brittany needed to be admitted to Johns Hopkins immediately. I was terrified! Was Brittany going to be taken away from us after only 12 very short days?

Mike and I rushed Brittany to the hospital. Dr. Lane Rutledge was there to meet us. After initial checks were made, we were told that Brittany had classic maple syrup urine disease. Mike and I were in shock. We'd never seen any problems in either of our families. It was decided that hemodialysis would be used to bring Brittany's levels down to manageable levels. We learned recently that her leucine levels had been approximately 2700 micromols (35 mg/dl) at that time.

Brittany was moved to the Neonatal Intensive Care Unit where they used hemodialysis. Several times we were asked to leave the room; one of these times, Brittany stopped breathing and was put on a respirator.

The next day, we were given more information on the nature of maple syrup urine disease. We were then allowed to begin feeding Brittany her first bottle of the special formula. Ten days later, she was released from the hospital and sent home.

Brittany's growth through the years has been above 50th percentile, in both height and weight. She has met every developmental stage. On March 27, 1990, Brittany's sister Taylor joined the family. From Taylor's development, we were able to better judge if Brittany developed "normally." So far, they have been almost identical in this arena (and believe me, that is the ONLY place they are anything alike).

Brittany had around four hospital visits due to elevated amino acid levels. In addition to these, there was a period of time when the doctors were testing whether she might be thiamin responsive. However, due to problems in managing her levels, it was judged that there was absolutely no response to thiamin.

Brittany's hair began to break when she was around 5 years old. It took us a while to notice it and associate it with low protein. Up until that point, Brittany had always gotten rashes around her mouth whenever her amino acid levels were too low. After increasing her total protein, it took nearly two years to grow all her beautiful red hair to one length again.

Brittany's last hospital visit was this past December. She had started with the flu on a Thursday, and was unable to keep anything down, including her formula without the whole milk. Neither Mike nor I were terribly concerned, because there had been instances of flu, colds, chicken pox, etc. in the past couple years without any episodes. But when Brittany woke up Friday, we knew immediately we would be making a trip to the hospital. She was very ataxic, and acted exceedingly goofy - if it hadn't been such a concern, it would have been funny.

Since we moved to Columbus, Indiana in 1992, we are treated by Dr. Rebecca Wappner at Riley Hospital in Indianapolis. We called Riley to determine where we needed to go for the IV treatment. Dr. Brian Hainline was on call and stated that we should come up to Riley immediately. Brittany was put on an IV Friday morning. However, by 5:00 Friday evening she seemed to be getting worse, not better. By this time, she was having memory lapses

and didn't know who Mike and I were. (Anyone who read Dr. Morton's article on brain edema in the last issue will understand that these were the symptoms we were seeing.) Needless to say, I was in a panic. I called Joyce and Wayne Brubacher (practically in hysterics), who gave me much needed moral support. After a discussion with Dr. Hainline, the IV drip was increased above a maintenance level.

By 8:00 that night, Brittany was beginning to hold her mouth more normally (it was very slack all day up until this point). Mike and I began to feel reassured that things were going better for our baby. Interestingly enough, when Brittany was again able to eat, she had a real craving for salty foods, like potato chips. Just goes to show that the body knows its needs.

Brittany was released from Riley that Sunday. Looking at her that day, it was hard to believe that she was the same person who had come in with us the Friday before.

Brittany continues to do well physically and in school. She is now in second grade, and her last report card was all A's and B's (sorry, a little bit of mother's bragging). She's involved with dance, loves to swim, read, color and rollerblade. The doctors continue to be very pleased with Brittany's progress. Mike and I are taking Brittany to the hospital fairly often right now, as we are trying to readjust her diet to ensure that she is getting the proper amount of amino acids.

My common response to those who ask how Brittany is doing is, "So far so good." We continue to be "so far so good" and my hope for you is that you all continue this way too.

FOOD FOR THOUGHT

Details

Written by Joyce Brubacher

Published: 17 July 2009

Adapted from two articles published in the National PKU News

Helping your child on a special diet eat right

Persuading a child to eat different and nutritious foods, whether or not the child has special health care needs, can be an exhausting and frustrating experience. However, you can help your child develop positive attitudes about nutritious foods.

Children learn best by example. Remember, your child wants to be like you. If the child sees you eating more salads, fruits and vegetables, he or she may want to do the same.

Listening to our kids

My bright, six-year-old son, Jeffrey, has phenylketonuria (PKU), a metabolic disease that requires him to follow a low-protein diet regimen. This means plenty of substitutions when his friends may be eating "funner" food. When a special diet is a lifelong requirement, it is important that children develop a sense of responsibility for what they eat. At the same time, it is important to allow them to express their feelings about the diet. We can learn a lot by listening carefully.

For example, Jeffrey recently said to me, "Mom, I really liked the 'peanut butter' (actually a low-protein substitute) and jelly sandwich you put in my lunch box today." I realized that this sandwich was more than just a tasty lunch. I knew that it also boosted Jeffrey's self-esteem to be able to eat food that looked similar to that of his peers.

Another time Jeffrey came home from school, sad and dragging, and said emphatically, "I don't like this diet!" Together, we figured out he was unhappy because he couldn't eat a hamburger. Regular hamburgers had too much protein, but together we came up with an acceptable substitute - low protein mushroom burgers. As parents, we have to follow medical advice, but we can still learn to listen to our children and creatively manage their diets. Children appreciate being able to express their feelings openly and having their needs treated respectfully.

A voice and a choice

Parents can reinforce a sense of responsibility in children by giving them a voice and a choice in matters that affect them. Severely restricting your child without explanation can lead to immaturity and rebellion. Children will accept "rules" more readily when explanations are given. Although health conditions may limit some options, we can help children accept inevitable choices gracefully.

Parents can involve young children in food choices by talking about them. For example, a two-year-old can decide whether he wants a half glass of "milk" or a full glass. A four-year-old can be asked if he wants an apple or an orange, or whether he wants his bread toasted or plain.

Children can be deliberately presented with many situations in which they have to make choices and are given chances to succeed. We can creatively select the situations and let children make the choices. This sends a clear message that children are not just recipients of "orders," but participants in decisions that affect them.

For example, when Jeffrey was very young, I always kept frozen low-protein bread and pancakes in Ziploc bags in the freezer, on a low shelf at Jeffrey's eye level. I would let him choose between bread or a pancake by responding verbally, by pointing or by actually getting it out himself. This made him feel that he was "in charge," and was a very small step toward dietary self-management in the future.

I also kept a variety of fresh fruit and vegetables in the lower part of the refrigerator so Jeffrey could see the choices between tangerines, grapes, plums and other fruits, or the choices between lettuce, carrots, celery, tomatoes or cucumbers in the vegetable crisper. The pantry was set up the same way with small cans of fruits and vegetables on the lower

shelf so I could ask Jeffrey, "Do you want carrots or green beans?" or "Do you want Mott's peaches or a Strawberry Fruit Pak?" He would go to the drawer where the measuring cups are kept and hold a cup up to the item he wanted.

Introducing new foods may take some effort. However, you will be rewarded quickly when you see your young child making the right choices from a smorgasbord of food. You can help your child develop tastes and preferences that last a lifetime.

This article was adapted from two pieces by Marsha Magol that first appeared in *National PKU News*. The article is reprinted from the Aug. '95 issue of exceptional Parent, a monthly magazine offering practical information to parents and professionals involved in the day-to-day lives of children and young adults with disabilities. For subscription information phone 201-634-6550.

Marsha Magol is a regular contributor to the National PKU News. She, her husband and one son live in Tampa, Florida, where Marsha works for GTE. She works nearly full-time and in the spring/summer '95 issue of the National PKU News she gave some planning and organizing tips for busy mothers who need to manage diets. Following are several ideas she mentions in that article which may be helpful to MSUD moms as well as others dealing with special diets.

- It works best to set aside a few hours one day a week to focus on low protein cooking like baking low protein bread and making, pizza and soup.
- Involve your child by asking, "How would you like to help me press out this pizza dough into big circles?" Encourage your child's participation in diet preparations at an early age.
- Prepare in abundance while you have your recipe book out and refrigerate or freeze as much as you can for those harried nights. Have your own ready-to-eat convenience foods.
- Make lots of pasta, regular and low protein, at least twice a week. Then have meatless tomato sauce on Monday, low protein cheese-flavored sauce on Tuesday, and pasta added to vegetable soup or stir-fried vegetables on Wednesday.
- Keep a lot of pre-cut vegetables and other foods that are almost ready to cook in plastic containers to combine in a 5-minute stir-fry.
- Keep things in perspective - you can't have "perfect" meals every night. (When Marsha looks back, she thinks about all the low protein food and recipes Jeffrey has grown accustomed to and enjoys - not whether the house was always clean or laundry piled up for days.)

SUBSTITUTES FOR MILK & ICE CREAM

Details

Written by Joyce Brubacher

Published: 17 July 2009

Recently I discovered Rice Dream Non-Dairy Beverage and Rice Dream Non-Dairy Frozen Desserts in our new local health food store. They seemed to be quite low in protein, so I bought some for Shayla to try. She was delighted to find products that taste so nearly like real milk and ice cream. This is the first time she can actually pour a "milk" directly on her cereal without diluting rich non-dairy creamers. This rice-based beverage looks more like skim milk. I found it tasty with a mild "ricey" flavor.

I called the company to find out more exact nutritional values and was thankful for the very low protein count. However, as frequently happens, the products have not been analyzed for leucine. They claim it is nearly impossible to test for amino acids in such minute quantities.

The Non-Dairy Beverage containers list the protein as 1 gm per 8 fl oz. The company gave me the analyzed amount as .303 gm per 8 oz. That is low enough to be listed as free protein on packages since 1 gm can mean anywhere from .5 to 1.5 gm of protein. The non-dairy dessert has the , cup serving size listed as 1 gm. The analyzed amount is .363 gm per , cup. So Shayla can make a tasty "milk" shake using 1 cup of "milk" and , cup of "ice cream" for .66 gm÷a little over a , gm of protein. Both products have 130 calories per serving.

The beverage is available as regular, enriched and vanilla enriched. The frozen dessert flavors include Swiss almond, vanilla, lemon and mint carob chip. It looks and tastes like ice cream. The prices are not unreasonable. It is marketed by Imagine Foods, Inc. in Palo Alto, California.

They also market Imagine Pudding Snacks and Rice Dream Non-Dairy Frozen Bars which have only 1 gm of protein per cup or bar. That is a rounded figure which could be considerably less if listed in the same way as the others. The company is doing more analyzing, since they have received requests. We will try to keep you informed.

THE HISTORY OF OUR SUPPORT GROUP - PART 2

Details

Written by Joyce Brubacher

Published: 17 July 2009

Continued from **Vol. 13, No.2**

The first installment of this article appeared in the last Newsletter (Winter 1995-96). In that issue I gave a brief glimpse of our personal family history and our early contacts with other families. That article also reported on our first family/professional Symposium (conference) which was held in 1982 at our local parochial school with almost 100 attending. The Symposium came about because of our desire to learn more and to share with other families. The following continues the story of the development of our MSUD Family Support Group.

At our first symposium, we discussed the impracticability of continuing our circle letter which had served as a means of sharing until this time. It was taking too long to circle with the growing number of families scattered throughout the U.S. and Canada. We considered starting a newsletter and elected to have a symposium every other year.

The first MSUD Newsletter was published in February '83. I gathered information and sent it to Patty Swenson (mother of Sanse with MSUD) in Englewood, Colorado. She retyped all the information and articles, formatting them on legal sized paper, and then xeroxed them at her husband Larry's office. She also did some of the writing and mailed the newsletters. Larry and Patty did all this voluntarily, donating their time and materials.

That first Newsletter consisted of seven, well-filled, legal-sized pages plus a page listing 28 families with their addresses, number of children with MSUD (32) and their birth dates. It included a questionnaire to be filled out by all persons interested in receiving the Newsletter. Patty's history of their daughter, Sanse, in that issue was the first in our continuing series of family histories.

In our second Newsletter (Nov. '83), we reported some statistics from a survey by Virginia Schuett entitled "Treatment Programs for PKU and Selected Other Metabolic Diseases in the U.S.: A Survey." The survey reported that as of June 1982, there were 115 MSUD cases currently being followed in the U.S. Of these 73 were classical, 13 thiamine responsive, 23 other diagnosed forms and 6 for which a more specific diagnosis was unknown. By then we had contact with 35 families involving 49 children. Our goal was to give the remaining families the opportunity to contact us if they wished.

Peter Shaffer and his wife, Sharon, from Kentucky had spent considerable time and effort sending over 200 form letters to major medical centers in the U.S. and Canada in April '83. This notified them of our organization and encouraged medical professionals to give Peter's address and phone number to parents of children with MSUD. The mailing was made possible by the Genetic Testing, Counseling and Education Services Program at the University of Kentucky Medical Center which provided names, addresses, materials and photocopying services.

Peter had also consented to be our treasurer. In the second, Nov '83, issue of the Newsletter we asked for a donation of $5 to be sent to Peter with checks made out to Families with MSUD - our organizational name at that time.

In this same issue, Sue Ann Frederick from Wisconsin shared a paper she had written for one of her high school classes. It described MSUD and told of her own diagnosis and

childhood experiences with the disease. One statement she made, "My body chemistry may not be able to handle all the changes of pregnancy, so I may not be able to have children," is of special interest considering the cover story later in Vol. 8, No.3 (Dec. '90). A picture of Sue Ann (Frederick) McKnight's baby accompanied an article Sue Ann wrote about her successful pregnancy experience and the birth of her perfectly normal little girl. She proved it possible, although it may not be safe for all women with MSUD to have children. The maternal concern had been covered earlier in the March '90 issue.

Patty and I managed only one Newsletter in '84 and one in '85. The '85 issue was 17 legal-sized pages with another questionnaire attached - probably our largest Newsletter. Patty and I were both very busy as I said in the next Newsletter - we squeezed Newsletters out through nooks and crannies of our very busy schedules. Patty and I also attended the "Genetics Support Groups: Volunteers and Professionals as Partners" conference in Washington, D.C. in the summer of '85. Patty reported on the meeting in the Feb. '86 issue.

One of the "extras" that interfered with publishing a 2nd issue in '85 was Shayla's accident. In July of that year, I had a doctor's appointment and told Shayla she could ride her bicycle down the road to her Aunt after she finished her work. She turned to cross the road suddenly because she forgot something. A car hit her in the passing lane. She was thrown onto the car windshield, shattering it, and then into the yard, narrowly missing a tree and mailbox. Her bike was demolished. In pain and bleeding badly from the head, she tried to get up and run to the house - it took a great deal to keep Shayla down in those days.

The paramedics expected serious head and neck injuries. I met her in the emergency room and knew she was fine because she was talking constantly - typically Shayla (Wayne says typically Mom, too). She was home again that night with a very sore body, some deep cuts and abrasions, and a broken collarbone. She healed rapidly and was doing some housework by the second week. However, she soon started having headaches which have plagued her since.

I wrote, "It is rather ironic that this accident brought many visitors, cards, gifts and expressions of concern, whereas a bad case of the flu is so much more critical. Therein lies the difference between the MSUD child and those without MSUD."

Personal accounts of the children like this account of Shayla's accident were frequent in the early Newsletters. There were reports of children having tonsils or teeth removed and their reactions. Peter and Sharon Shaffer's Jessica falling off a 10, foot wall holding her formula in a glass with a lid and not spilling a drop. Peter said, "In the kitchen it always goes all over." New births and deaths were reported with some details. Various accomplishments of the children were described and observations made such as - MSUD children have a keen sense of smell. They gag easily at bad smells including their own bathroom smells which can create embarrassing problems.

We had good reader participation in the early Newsletters. Our sections on "MSUD Family News," "Low Protein Recipes," "MSUD Featured Families" and "MSUD Parent Question and Answer Exchange" were well supplied. In the third issue, April '84, we printed the first professional article reviews. That issue included reviews of presentations given at the '83 conference of the Neuro-Metabolic Disorders held in Ann Arbor. These conferences are still a source of information for our Newsletters.

Patty typed the two '86 issues of the Newsletter, but had them printed in the letter-sized format we still use. Patty had an artist design our present logo for the February '86 issue. It first appeared on the masthead of the November issue. That Newsletter had a little over 18 pages, but the type was larger than our current print.

For the first '87 issue Patty sent the information to a printer. It was typed on their computer, but Patty mailed them. It was decided that I could do the same thing here. Patty had fulfilled a very important role in getting our Newsletter off to a good start. She and Larry did not spare of their time, money and facilities and deserve much credit for the early success of the organization.

I was thankful for a printing firm just two miles up the road from us. This firm was owned and operated by the Stanley Brubaker family (no relation). However, they were friends and went far beyond the call of duty helping with the Newsletters. My typewritten pages with corrections in the margins were taken in stride. They tolerated my last minute rush requests with calm reassurance. I am sure they could have sympathized with Patty.

In Dec. '87 we included pictures for the first time. Pictured were Elan Geffen from Virginia, Michael Toth from Ontario, Canada and Laura Henry from Great Britain. We had gone international.

I published only one 7 page Newsletter in '88. This is the year we designed and built our current house which involved a lot of my time. An 18 year old friend of Shayla's, who had helped me with the typing for the '87 issues, was killed in a tragic accident soon after the Dec. issue was sent out. Nineteen eighty-eight was an exhausting year.

I tried to make up for it by getting 3 issues out in both '89 and '90. Since then I have been back to publishing only 2 issues a year. Other changes made during these years included:

- Family Contact Person, Bonnie Koons from Pennsylvania, and Professional Contact Person, Alice Mazur, R.N., P.N.P. from CHOP in Philadelphia were added to the masthead in June '89. The format changed again in May '93 with the addition of Mary Kathryn Martin as Food News Editor and Kelly Green, R.D. as Recipe Editor.
- We added a Kid's Klub children's section as an insert beginning with the Nov. '89 issue. Bonnie Koons did a great job on this section, but unfortunately after several issues, it was discontinued for lack of response. Lack of input caused the demise of other Newsletter sections over the years.
- I used a friend's computer to type the '91 issues while she did the final formatting for me. In '92 we bought our own computer thus opening up the whole new world of formatting for me.

Other organizational changes, improvements(?) and accomplishments during these first 13 years:

- At the second Symposium we discussed printing a Free Protein Food List. I compiled a list of "free" foods using Virginia Schuett's Low Protein Food List and the Lo-Pro Guide from the Metabolism Clinic, Riley Hospital, Indianapolis, IN. Later the list was printed on a card to be handed to persons involved with the care of a child with MSUD. It fell by the wayside for lack of interest.

- Information packets were proposed in the April '87 issue of the Newsletter. Bonnie Koons helped gather the materials and began making them available to new families in '89. She continued until she handed over the reins of contact person to Dawn Hahn in '93. The packets are being upgraded at this time. Dawn is in charge of distributing them.
- After several years of trying to find a professional who would write a brochure describing MSUD, several families gathered to brainstorm. With this help I wrote an information sheet. Later we were able to finance a brochure which was recently updated.
- In Dec. '90 the subscription rate increased to $10.00 and a prayer hot line was started for those who wished to be involved.
- At a business meeting in April '89, we discussed becoming a nonprofit organization. We were small enough that it was not essential, but we were growing. Irv Geffen, who lived in Virginia at that time, assumed the responsibility to tackle the job. We were legally incorporated in Virginia in 1990. Irv graciously paid the yearly legal fees for the next couple of years. It wasn't until '93 that all the red tape was unwound and we had our nonprofit status. We have always operated on a nonprofit basis using volunteers.
- Board members were elected at the Symposium in Montreal in June '90. Even though being so scattered creates a problem for face-to-face board meetings, they all have served faithfully:
    - President- Wayne Brubacher, Goshen, IN
    - Vice President- Sharon Shaffer, Flemingsburg, KY
    - Bonnie Lou Koons- Secretary, Harrisburg, PA
    - Peter Shaffer- Treasurer, Flemingsburg, KY
    - Irving Geffen- Cherry Hill, NJ
    - Joseph Balinsky- Hampstead, Quebec
    - Barbara Rudd- North Adams, MA

Many persons have been involved in keeping the MSUD Family Support Group a growing and evolving organization. One very hard working group I haven't mentioned yet - those who organized and sponsored the Symposiums. Here is a list of the Symposiums to date.

DATE	**PLACE**	**FAMILY SPONSOR**
5/82	Goshen, IN	Wayne Brubachers
6/84	Flemingsburg, KY	Peter Shaffers
6/86	Denver, CO	Larry Swensons
6/88	Hinkletown, PA	Pennsylvania Families
6/90	Montreal, Quebec	Joseph Balinskys
6/92	Toronto, Ontario	Toths & Sullivans

6/94	Columbia, MO	Missouri Families

Medical centers in each of theses areas were very helpful and supportive and sometimes did a major part of the planning. Professionals and families working together can accomplish so much. Sandy and Dave Bulcher in conjunction with the University Hospital in Ann Arbor, MI are working hard on the next Symposium in Columbus, Ohio.

Two other persons I want to acknowledge are our daughter, Shayla, and my "teacher" and indispensable helper, Martha Stern. Without Shayla to carry on the housework when Mom is glued to the computer, I could not spend the time necessary to do the Newsletter and the many other necessary tasks.

Martha came into my life soon after I started working on a computer. She is a very keen editor and great teacher. She has the eye of an artist and the patience of Job. She is a behind-the-scenes major asset to the organization and lives less than 10 miles from me. The rest of you seem so far away.

Tish Fuller faithfully puts all the information I send her on disk. This is a great benefit and I truly appreciate it. And last but not least is my long-suffering husband who puts up with a tense bundle of nerves at least twice a year.

Above all the Lord has blessed this organization and without His blessing we would fail. Thanks be to our gracious loving Heavenly Father in whom I trust.