NATIONAL ICHTHYOSIS FOUNDATION
A NON-PROFIT CORPORATION

The National Ichthyosis Foundation

ICHTHYOSIS FOCUS

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Published Six Times a Year by volunteers of The National Ichthyosis Foundation, P.O. Box 252, Belmont, CA 94002. Telephone (415) 591-1653. NIF is a non-profit California corporation, for the benefit and education of its members and the public regarding medical, psychological and social aspects of ichthyosis, a genetic skin disorder. Letters, suggestions and contributions are welcome. Valerie Lutters, Editor.

FROM THE EDITOR'S DESK

Welcome to spring! I think nearly everyone welcomes the coming of spring, but people with ichthyosis are probably even more enthusiastic than the general public. After all, we get the same benefits everyone else does -- no more snow, no more struggling with kids' snowsuits, no more fuel bills, beautiful flowers and longer days **PLUS** a bit of relief for that dry skin that itches and scales worse in the winter for so many of us. Why, even Santa Claus probably wouldn't say "Ho Ho Ho!!" in the middle of winter if he suffered from ichthyosis!

Spring brings a few nice holidays, too, like **Mother's Day**, falling this year on May 11, and **Father's Day** June 15. If everything goes on schedule (a big "if," I admit, but we'll Think Positive), the third issue of Focus '86 should be arriving in your homes sometime between those two holidays, and so I'd like them to be the theme of that issue. Nearly everyone has countless things for which to be grateful to their parents, but I suspect that those of us with ichthyosis have even more. After all, moms and dads of children with special problems have a whole set of special problems of their own.

So -- I'm looking for some grateful kids and as well as some grateful former kids to write in and tell our members some of the things their moms and dads did to make life with ichthyosis a little easier -- things to make you more comfortable physically, things that helped your self-esteem or your relationships with peers, anything that comes to mind. I'd like to publish a verbal collage of remembrances, thank you notes, etc., and dedicate the issue to all those ichthyosis parents, past and present. I won't publish any names unless you specifically ask me to, but I **would** like you all to include your age and your sex if you are under 20 or so. Young children may include illustrations, too, if they like. Because of space limitations, I can't promise to use them, but I'll try.

Send your comments within two weeks of getting this newsletter so we can get the special issue out to you sometime between those two holidays to make it as timely as possible.

Worth a Thousand Words: Many of you are probably aware that the National Ichthyosis Foundation is putting together two brochures on ichthyosis to be used for a number of purposes, including education of the general public, health professionals, and families newly stricken with ichthyosis. We're also hoping to make strides towards more publicity about this disorder about which so few people know anything at all. And in May a Foundation representative will testify before Congressional scientific research appropriation committees to obtain increased funding for national skin research.

There's a definite, tangible and immediate way members can help. As the saying goes, a picture's worth a thousand words, so we'd like to collect a portfolio of photographs of all the varieties of ichthyosis. People who have never seen ichthyosis and merely read descriptions -- "scaly skin, redness, blisters" --can't always appreciate just how serious it can be, but a picture can say plenty. Also, pictures aren't just pictures of skin; they're pictures of people, often little people. Thus, while words can be coldly factual, pictures emphasize the human element.

We need pictures of adults and children and babies: faces, arms, legs, backs, etc. Medical-textbook type pictures, family pictures, **any kind.** We want to show researchers, politicians, and people from every walk of life. We want to show ichthyosis, and we want to show that it's only skin deep.

Every picture must have **information on the back** to tell us who the person is, his or her age and sex, and the kind of ichthyosis shown. Any other information would be helpful, too. We also need a written and signed basic **Photo Release** to give us permission to use the picture. On a separate sheet of paper, (typed or handwritten), please prepare a Photo Release, saying you give NIF permission to use the photograph(s) for educational, research or promotional **purposes.** We cannot use any picture without both identifying information and a basic Photo Release. Naturally, we won't publish or otherwise distribute any names or identifying information, but we do need this information for our own files.

It is the policy of NIF not to use any picture that shows a face unless we also have **additional Special Permission** of that person (or their parent or guardian). If we want to use the picture you send with the basic Photo Release, we will send you a Special Permission form. The decision is yours.

Betty McMasters has 3 oz. jars of **Vaseline Dermatology Formula Cream** that were donated to the Foundation and she will send some to anyone interested. Call or write to Betty for details. Her address and phone number appear at the end of the listing of Chapters and Regional reps in this issue.

TELL ME, DOCTOR

QUESTION: "I heard that at the annual conference in Las Vegas, Dr. Mary Williams suggested that what has always been called Lamellar Ichthyosis is now being broken into two separate categories. I'd like to learn more about this."

Dr. Williams and Dr. Peter Elias responded to that question as follows:

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Two Types of Lamellar Ichthyosis. In the current classification of the ichthyoses, "Lamellar Ichthyosis" has been the traditional term for those patients with a moderate-to-severe form of ichthyosis that is life-long (i.e., present at birth) and involves the entire body surface. Facial involvement commonly leads to tension on the eyelids and may result in an inability to close the eyes completely (ectropion). In addition to the scaling (ichthyosis), the skin is quite reddened (erythrodermic). This form of ichthyosis is inherited as an autosomal recessive trait. On skin biopsy, the histology does NOT show epidermolytic hyperkeratosis (EKH), (the most prominent finding in bullous [blistering] ichthyosis); also the enzyme, steroid sulfatase, which is absent in recessive X-Linked Ichthyosis, is normally present. Thus, diagnosis of "Lamellar Ichthyosis" has involved: 1) conformation with the clinical features outlined above; and 2) exclusion of other forms of ichthyosis, both by skin biopsy and, when indicated, by tests to exclude steroid sulfatase deficiency.

This lumping of patients with these characteristics into a single entity, "Lamellar Ichthyosis," has not been universally accepted, however. Some authorities, notably in Europe, have recognized a second form-- "Congenital Ichthyosiform Erythroderma" (CIE); nonetheless, the rationale for such a division was not well-established until recently when we and others discovered that "Lamellar Ichthyosis" represents two distinct diseases, of which one disease entity would still be called "Lamellar Ichthyosis" (LI) and the other, "Congenital Ichthyosiform Erythroderma" (CIE). There are clinical, histological and biochemical differences between the two diseases; and in the few families where more than one affected family member has been examined, there is agreement as to type (i.e., either all have LI or all have CIE), further suggesting that these are genetically distinct diseases.

Briefly, the differences between these two disease are: **Classical Lamellar:** 1) LI appears to be somewhat less common than CIE. 2) LI is a uniformly severe form of ichthyosis; all patients have large, dark, plate-like ("lamellar") scales all over their bodies. 3) ectropion is always present and often severe, but redness (erythroderma) may not be prominent. 4) the skin biopsy shows a marked thickening of the outer horny layers of the skin (stratum corneum). 5) measurement of epidermal proliferation rates (how rapidly skin cells are multiplying) shows them to be normal or nearly normal. In contrast, **Congenital Ichthyosiform Erythroderma** (CIE): 1) has a more variable spectrum of severity; some patients have relatively mild disease while others have very severe disease; 2) Some people get better at puberty while others develop a form of hair loss termed "cicatritial alopecia." 3) the scales on the face, trunk and arms are smaller, thinner and whiter than in LI. 4) ectropion may not be present. 5) erythroderma (redness) is often very prominent. 6) the skin biopsy shows greater thickening of the living epidermis relative to the horny layer than does LI and it may be "prematurely" formed (termed "parakeratosis"). 7) in CIE, rates of epidermal proliferation are increased. And finally 8) examination of the scale lipid (fatty) profile demonstrates accumulation of certain very saturated lipids, hydrocarbons (long-chain n-alkanes).

We have much to learn yet about these two diseases. In neither is the underlying cause known. Until it is, this classification can only be considered to be provisional. If you would like to discuss this further with your doctor, the information given above has been published in the **Archives of Dermatology**, volume 121, pages 477-488, 1985.

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Drs. Williams and Elias note that because of the rarity of these disorders individual investigators can amass only limited experience with them. They feel that the members of the Foundation can help researchers gather information regarding: 1) How do these conditions appear at birth? 2) What is the spectrum of severity **within** families versus **between** families? And 3) Are there other problems such as physical growth, etc., that may be related to the ichthyoses? Drs. Mary Williams and Peter Elias need patients with the CIE-type of ichthyosis as volunteers to be available for future studies on the cause and treatment of this type of ichthyosis. Anyone willing to volunteer for such studies should please get in touch with them directly by writing or calling:

Dr. Mary L. Williams
Dermatology Service (190)
Veterans Administration Medical Center
4150 Clement Street
San Francisco, CA., 94121
(415) 750-2091

HOT TIPS

"Hot Tips" are bits of practical information from many sources. Neither the Foundation nor the Medical Advisory Board recommends any particular "tip." We do not provide medical advice, nor do we endorse any particular product. N.I.F. acts only as a clearinghouse of news. Ask your doctor about any tip and follow his or her advice before acting on any information presented in this forum.

A number of members report that they achieve good results from using **occlusion**. Occlusion is a method of sealing moisture into the skin for a prolonged period of time using a material that is not permeable to air or water -- plastic, for instance. Occlusion suits, sometimes called sweat or sauna or exercise suits, are typically a pair of long pants and a long-sleeved top resembling a sweat suit but made of plastic, sometimes nylon. They have elastic or drawstrings at the waist, neck, wrists and ankles. They are available at sporting goods stores and through many pharmacies.

People with ichthyosis use occlusion to hydrate their skin. Usually they take a shower or a bath to get the skin really moist, then jump into the suit with little or no toweling off. Sometimes they put on some kind of moisturizing lotion, or a spray of 50-% water and 50% propylene glycol solution before donning the suit. Then they spend a few hours with a good book or go to bed for the night with the water and any other moisturizing agents all sealed up inside the suit. Without any air getting to the skin to dry it out, the water, especially if it is aided by propylene glycol, penetrates the skin and makes it very soft.

The next morning finds the person feeling profoundly clammy, but not without rewards. The softened skin will slough off in the shower, with minimal urging from a washcloth, in quantities that are downright impressive. Since the skin has been so well softened ahead of time, it can usually be rubbed off so gently that the skin below remains intact--smooth, pinkish and a little delicate. Just don't forget you still have ichthyosis, and it's still important to lubricate your skin or the scales will be back, dryer than ever, quicker than ever. Use a moisturizer-- perhaps one with an alpha hydroxy acid in it, like LAC-HYDRIN from Westwood or AQUA GLYCOLIC from Herald. Occlusion is a treatment, not a cure, of course, and scaling will build up again. Still, for many members, it is very effective.

Drawbacks? Yes, it has a number of drawbacks. It's a royal nuisance, for one thing. The suits frequently get stiff from lubricants, detergents, etc.: stiff enough to eventually stand alone in the middle of a room and to snap, crackle and pop when you roll over in bed while wearing one. If they get stiff and hard enough, they can almost cut the skin in which case it's definitely time to get a new one. They are also rather unattractive as evening wear. You tend to look like an astronaut or an escapee from the 4077th M.A.S.H unit when you wear them. Many people combine the suits with some home-style additions for **total** occlusion (plastic shower caps for occluding the the scalp, plastic wraps to occlude the neck, rubber gloves on the hands). You probably won't want to answer your doorbell in such an outfit. Some patients feel they are too hot, although wearing just a top or bottom, or cutting down on the time can help. Some patients treat only small, severely affected areas, like an arm; plastic food wrap such as Saran Wrap has been used with success for occlusion of individual body parts. The plain plastic suits wear out in less than a year. A new style suit, made of softer and stronger nylon, lasts longer and is more comfortable than the traditional plastic type, but doesn't hold moisture or heat quite as well. It may be best for those who find a plastic suit too hot, or who use a cream or lotion, instead of a watery solution inside the suit.

Treatment and response vary from individual to individual and with the type of ichthyosis involved. As always, check with your doctor first; some pharmacies require a prescription for an occlusion suit anyway. Many members find occlusion to be a very satisfactory, (if inconvenient), form of treatment. And you'll never be without a truly unique Halloween costume ever again!

Soft Touch -- Several members have written in saying that using water softeners has helped them a lot. It seems that water is good, but soft water is even better.

And one more tip about moisture -- a member tells us she uses a **humidifier** to keep the air moist in the winter when central heating can dry out the air. And in the summer, when it gets terribly hot (and people with ichthyosis know all about being hot!), she carries a **spray mister**, the type used for misting plants, with her, especially in the car. Sort of like manual perspiring when your skin won't let you do it the usual way.

Tax Tip -- Occlusion suits, water softeners, misters, and humidifiers may all be tax deductible as medical expenses. Ask your tax advisor.

SOME PARTING WORDS FROM N.I.F.'S OUTGOING CO-PRESIDENT

Charles L. Eichhorn, N.I.F. co-president and former editor of **Focus**, will be stepping down when his term of office expires this April. Co-president Susan SeHaan remains in office until December.

During his years as a co-president Mr. Eichhorn has devoted countless hours of his time, immeasurable expertise as an attorney, and boundless energy to the Foundation. Both Mrs. DeHaan and Secretary/Treasurer Jeannett Jensen who have worked closely with him during that time, praised Mr. Eichhorn's leadership and dedication, noting that the Foundation has grown and flourished under his guidance. "He set up the survey; he did the newsletter; he initiated the annual conferences; he put us in touch with legislators and other skin organizations; he traveled and attended meetings; he got things done when he said he would. And he's a great person to work with," said Mrs. DeHaan. "I only wish the Foundation had about 30 or 40 more people just like him!"

Although Mr. Eichhorn assures the membership that he will remain a member of the Board of Directors and an active contributor to the Foundation after he retires as Co-president, there can be no doubt that his leadership will be sorely missed. Mr. Eichhorn, in turn, would here like to thank some of the many people who have helped him help the National Ichthyosis Foundation during the last two and a half years.

* * *

-Thank Yous -- I have a long list of people to thank for their help and support during my time as a leader in the Foundation. Here are just a few I forgot to mention when I was editing the newsletter last year: Susan DeHaan, LCSW, Jeannette Jensen and Dr. Mary Williams, for their vision, determination and support; Valerie Lutters, for her generosity and willingness to help with any project, in any capacity, at any hour; Paul Seliga, for prompt and unstinting help in getting our computer system in shape; Betty and David McMasters, and David's kind parents, for their active participation in N.I.F. and their genuine hospitality; Dr. Lowell Goldsmith for his loyalty and dedication in chairing the Medical Advisory Board through thick and thin and waking up for early breakfast meetings every year; Drs. Peter Elias, Joseph McGuire, Eugene Van Scott and Leonard Milstone for their generosity in sharing their professional knowledge at conferences year after year; the N.I.F. members who responded with whatever money they could afford when we needed it most; the children with ichthyosis all over the world who remind me the battle is not nearly over; and to my wife, Diane, who has given me time to do the work I must do, and who has made me understand, finally, that to really see if a person is beautiful, you must look much deeper than just the skin. Thank you all for letting me try to help.

N.I.F.'s THIRD ANNUAL CONFERENCE -- A FIRST TIME ATTENDEE's IMPRESSIONS

The Third Annual Conference of the National Ichthyosis Foundation was held at the Best Western Mardi Gras Inn in Las Vegas, NV, on Saturday, December 7, 1985. The morning sessions consisted of medical presentations by Dr. Mary Williams and Dr. Peter Elias, both of the Veterans Administration Medical Center, San Francisco, CA; Dr. Eugene Van Scott of Temple University Health Science Center, Philadelphia, PA; and Dr. Leonard Milstone of Yale New Haven Hospital, New Haven, CT. All four doctors are members of the N.I.F. Medical Advisory Board. The afternoon session consisted of presentations by Susan Nye DeHaan, LCSW, on the psychological aspects of ichthyosis and by Charles Eichhorn on the state of the Foundation; they are N.I.F. co-presidents. Also during the afternoon, Dr. Alan Moshell, Skin Diseases Program Director with the National Institutes of Health, spoke about funding for research.

William Geismann of Skokie, Ill., reports on the conference for **Focus**. He covered the morning session in the last issue and continues here with his report on the afternoon's activities.

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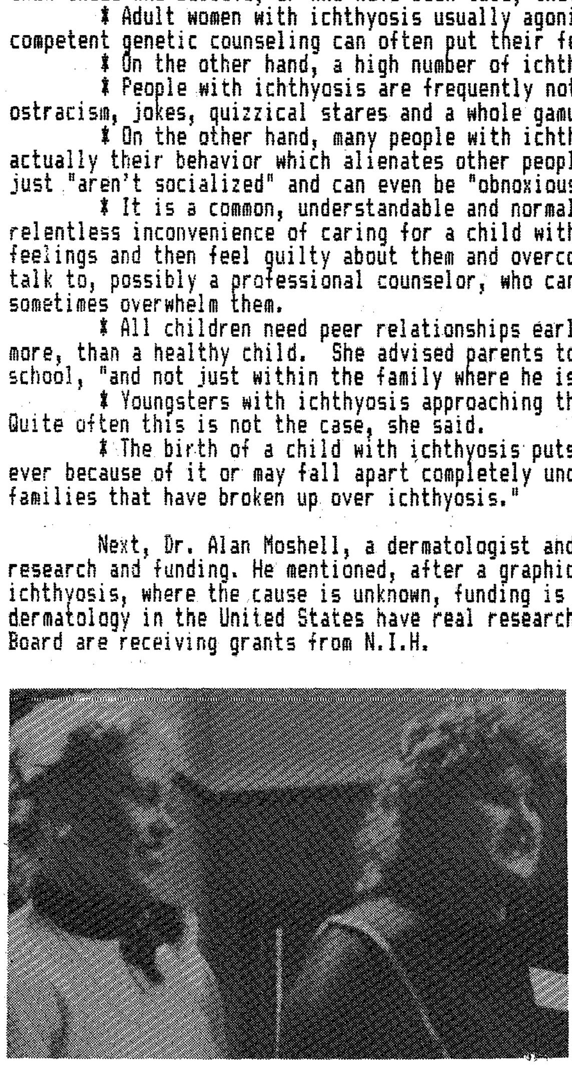
Susan DeHaan led off the afternoon session with a discussion of the psychological impact of ichthyosis. Discussing children, in particular, with ichthyosis, she emphasized that it is important for parents to see the whole child, not just the disease. "The skin is not the child," she said, advising parents to pay more attention to what the child can do than what he can't, and to emphasize his skills, abilities, and strengths-- in other words, to accentuate the positive.

When parents first find they have a child with ichthyosis, she said, their initial response to the trauma is usually shock followed by guilt, and their coping skills are severely tested. Some parents, she observed, never do get past the guilt. The next response, usually, is a search for the right doctor and a cure. Since there is no cure, even the "right" doctor will disappoint them, and since so little is known about ichthyosis, even doctors may be ignorant about the disease. "Regular dermatologists just don't see that much ichthyosis," she explained. Yet relatives, neighbors and friends seem to have all sorts of well-meaning suggestions....

Mrs. DeHaan went on to note:

* Ichthyosis is not the worst thing in the world, and it is important for its victims to keep it in perspective and not let themselves become a "prisoner of the skin."
* People with ichthyosis who come from an enlightened and informed background fare far better, psychologically, than those who believe, or who have been told, that ichthyosis is a curse brought on by someone's past sins.
* Adult women with ichthyosis usually agonize, sometimes needlessly, about having a child. A correct diagnosis and competent genetic counseling can often put their fears to rest.
* On the other hand, a high number of ichthyosis sufferers do marry, she finds.
* People with ichthyosis are frequently not as assertive as other people and allow themselves to be victims of ostracism, jokes, quizzical stares and a whole gamut of impolite behavior.
* On the other hand, many people with ichthyosis blame their disease for loneliness or lack of friends when it is actually their behavior which alienates other people who are often not even aware of the disease itself. Sometimes they just "aren't socialized" and can even be "obnoxious." They isolate themselves and hide behind the disease.
* It is a common, understandable and normal response for parents to explode at times under the burden of the relentless inconvenience of caring for a child with ichthyosis; to resent the burden of that care; to harbor conflicting feelings and then feel guilty about them and overcompensate by being overprotective.... She advised finding someone to talk to, possibly a professional counselor, who can help the parents unload and deal constructively with feelings that can sometimes overwhelm them.
* All children need peer relationships early in life, and the child with ichthyosis needs them as much, if not more, than a healthy child. She advised parents to make sure that their child had such relationships before he attends school, "and not just within the family where he is often overprotected."
* Youngsters with ichthyosis approaching their teens usually worry that they won't date because of the disease. Quite often this is not the case, she said.
* The birth of a child with ichthyosis puts a strain on the whole family which often pulls together stronger than ever because of it or may fall apart completely under the burden. "This disorder makes or breaks a family; we have families that have broken up over ichthyosis."

Next, Dr. Alan Moshell, a dermatologist and a member of the National Institute of Health (N.I.H.), spoke about research and funding. He mentioned, after a graphic description of the labyrinth of N.I.H., that with a disease such as ichthyosis, where the cause is unknown, funding is not specifically directed. He said that only 20-25 departments of dermatology in the United States have real research bases, and that most of the members of the N.I.F.'s Medical Advisory Board are receiving grants from N.I.H.



Betty McMasters, right, First Vice President of the Foundation and a local representative of the Oklahoma area, presented a check to N.I.F. Accepting the check on behalf of the Foundation is Susan DeHaan, Co-President. The Tulsa Chapter raised $2,000 through a benefit auction and other fund raising events. "It takes dedication...one day at a time...and hang in there," Mrs. McMasters said.

Rounding out the day's conference, Charles Eichhorn, Co-President with Mrs. DeHaan, took the rostrum to report on the overall state of the Foundation, its accomplishments and its goals. The N.I.F. began in 1981 and since that time has seen a "quiet revolution in ichthyosis. The information about this rare disease of the largest organ in the human body has increased tremendously in five years." After a roaring start, N.I.F. went through fianncial and leadership growing pains, and is now "moving" again.

The need now, he said, is for person-to-person contact throughout the nation. The local representative must be the key figure, bringing clear information and encouraging meetings between people with ichthyosis and parents of children with ichthyosis. N.I.F. needs a broad network of regional representatives working with patients, parents, hospitals, dermatologists, school nurses, and myriad others. He noted that most people with ichthyosis still have not met a single other person with the disease.

Mr. Eichhorn stressed the need for more volunteers. "The more we do for people, the more they expect of us," and "yet we don't get enough volunteers. You have to care. You have to be mad. We need the help of an angry mother or father ... I'm here becasue I'm an angry patient!"

A full-time, paid executive director could handle many of the duties of the organization, he said, but the money just isn't there to hire someone. Although many members have been very generous, most readers just don't contribute anything to the group's growth.

Another goal is education and it can be achieved, in part, through publicity. A lot of people in the media are interested in ichthyosis and the foundation, he said, noting that "to us it's embarrassing, but to them it's ... sexy."

Noting that the Las Vegas conference was attended by a record-breaking number of people, he said, "Never in history have there been this many people assembled around the subject of ichthyosis."

On a further optimistic note he directed people's attention to the November 1985 issue of **Business Week** and its article on "The Gene Doctors." He pointed to the article's positive outlook on the future of gene therapy which he felt was a "real hope if your afflicted child is quite young. Because it deals with the cause, not just the symptoms, gene therapy is really something to look forward to."

Mr. Eichhorn also reviewed, briefly, some of the preliminary findings that had come about as a result of the survey N.I.F. made approximately one year ago. The survey, mailed to 2,500 and answered by approximately 250 people, pointed out how badly the foundation's services are needed. For example, more than half of the respondents have not met anyone else with ichthyosis; many people don't even know which type of ichthyosis they have; many are confused about its genetic pattern and about the fact that it is, as yet, incurable. By far, the vast majority of people have learned about the foundation from printed articles, notably an article about N.I.F.'s first president, Barbara Landwehr and her daughter Deatra, in the national magazine **Good Housekeeping**. We need publicity, written publicity, to reach more people, he said.

More publicity, more representatives, more information, more services, more funds, more work..... The thrust of Mr. Eichhorn's presentation appears to be a trumpet call to all N.I.F.'ers across the land to join hands and get moving!

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BR. COLUMBIA: Valerie Munroe, 2492 West 45th Ave., Vancouver, B.C. V6M 2J8 Canada (Chapter)

We need informal representatives and support persons in every state and major city. How about you? Would you spend a few hours each month sharing information and "being there" for someone in distress? We particularly need help in the following areas, where there is no one for new parents to turn to:

Maryland
Missouri-Kansas-Nebraska
Vermont-New Hampshire-Maine
North and South Dakota-Wyoming-Montana
West Virginia-Kentucky-Tennessee
New Mexico-Arizona-Utah

Please contact **Betty McMasters, 1838 So. Muskogee, Sapulpa, OK 74066** (**Tel: 918-224-9099**) for details.

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