F.I.R.S.T.
Foundation for Ichthyosis and Related Skin Types

ICHTHYOSIS FOCUS

Vol. 12, No. 4 A Quarterly Newsletter for Friends of F.I.R.S.T. Fall 1993

SENATOR MARK HATFIELD INTRODUCES INTO CONGRESS THE "CENTER FOR RARE DISEASE RESEARCH ACT OF 1993"

The Act Will Establish A Center for Rare Disease Research At The National Institutes of Health

In comments before the U.S. Senate formally introducing his "Center for Rare Disease Research Act of 1993," Senator Mark O. Hatfield (R-OR) went to great lengths to relate his own experience with rare disease. He told of his personal relationship with sufferers of epidermolysis bullosa (EB), and how this personal contact contributed to the eventual funding of EB research and, ultimately, the development of a national EB patient registry.

In fact there are thousands of rare genetic diseases which affect the health and welfare of tens of millions of Americans. The Senator believes it is ridiculous to hope or expect that each of these disease-affected populations would find a sympathetic Senator or Representative to champion their cause on Capitol Hill. This was the heart the Senator's message: "Should research priorities be dictated by personal experiences like mine," said Hatfield.

"For me, that approach is too random," the Senator continued, "too dependent on fate and circumstance. The true need in this arena is a strategic plan—an effort to ensure that coordination of rare disease research is underway and that families have a point of connection to the system so that they may share their stories, find information, and work toward a better quality of life."

In the language of the bill (designated Senate Bill 1203), the Center's *purpose* will be "to promote and coordinate the conduct of research on rare diseases and to establish and manage a rare dis-

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See related story on Page 10
"A Five-Dollar Cancer Cure"

GRASSROOTS FUNDRAISER NETS $3,000

The LaBarbera Family Runs a Fund Raiser Out of Their Florida Business

Would you pay your boss $2.00 to take off your tie or shed your skirt, don shorts or dungarees and just plain dress down at work?

Long-time F.I.R.S.T. supporters Randy LaBarbera and his parents, Joe and Chris, thought the answer might be yes. Owners of the All-Brite Sales Company in Jacksonville, Florida, the LaBarberas this spring put together a large-scale fund raiser betting on that answer.

photo: Florida Times-Union © 1993

Billed as the All-Brite Sales Company Dress Down & Bake Sale Week for F.I.R.S.T., the LaBarberas passed out bright orange stickers that carried the F.I.R.S.T. logo and the words "I'm Dressed Down for F.I.R.S.T." to anyone who paid the

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The editor invites correspondence. Please offer us your comments, criticisms, observations and suggestions. Tell us what you wish to see and whom you wish to hear from in *Ichthyosis Focus.*

Please send your letters to us c/o *Ichthyosis Focus* at our office in Raleigh.

CORRESPONDENCE CORNER

George and Vera Hazaert of Green Bay, Wisconsin, write: "Thank you for the great conference in Chicago! It was all I expected and more. It was quite an experience seeing and meeting others who have ichthyosis. I had never seen anyone other than my son with this disorder. The reports on the research was very enlightening, and I wish the scientists God speed! No one should have to go through life with this condition."

In September we heard from **Barb Karas Klasell, of Escanaba, Michigan,** who tells us, "Since receiving my *Focus* newsletter and reading about others with ichthyosis, I can think of no better way to spend some of my wages! Enclosed please find another check, but please don't send another acknowledgement letter. Save the money for more important stuff you need.

"Recently I met a neighbor (5 miles away) with the same problem and we have shared stories, worries, an fears over coffee several times. We both wish we had met when we were children and could have lessened some of the burden of being 'different'. As children we both thought we were the only ones! It is the first time in my life I had someone who really related to my problems. This is very strange, as my brother has ichthyosis also, but in our family we never talked about it.

"I was unable to attend the conference in Chicago, but hope to in the future. We can never learn too much about ourselves and others. Your newsletter with pictures gave me another uplift ... I saw lots of shining faces (thanks to creams) just like mine in pictures. I am not the only one!

"Keep up the good work and support for the kids and parents. We really need to educate parents, and support them so they don't feel a failure or blame themselves. My mom died thinking that *she* did this to her kids (a doctor's explanation of how we 'got' the disease)."

Kathryn Jacobsmeyer of St. Louis, Missouri, writes: "My daughter, **Marirose,** who has Netherton's Syndrome, was fortunate to attend the American Academy of Dermatology (AAD) sponsored week-long camp at Camp Knutson (Minnesota). What a ***golden*** opportunity. I cannot sing the praises of the AAD and of the camp staff enough! **Mark Dahl, M.D.** [president of the AAD] and **Ruth Sikes** [AAD coordinator of the camp] attended, as did **Linda Rabinowitz, MD** and other dedicated professionals. This was an extraordinary opportunity, with a staff of warm and loving people. The AAD is to be *highly* commended."

Editor's Note: I want to echo Kathryn's remarks. Mark Dahl, Ruth Sikes and everyone else at the AAD who gave unselfishly of their time and energy deserve our heartiest congratulations. The camp proved to be a rare and precious opportunity for young people with skin diseases to share a carefree camp experience. Older children who themselves have skin disorders worked as camp counselors, and a platoon of medical specialists from many disciplines (all of them volunteering their time) rounded out the staff. I have been told that young people with ichthyosis made up the largest proportion of camp attendees. I know many of our members attended. We thank the AAD for their thoughtfulness and generosity, and we look forward to this being an annual event.

Justine and James Seman from Gulf Breeze, Florida, write: "Nick and Heather, you are doing a *great* job. I like the politics/lobbying efforts and articles. Heather's "Mother's Breakout" [in the last issue of *Focus*] was brilliant in its simplicity and unspoken need. I hope the men do it too next year [at the next national conference, in 1995]—give them a sweat lodge and some drums and fire to break the ice.

"Ellen Rowe ... we are all indebted to you."

Deadline for submissions to the next issue of *FOCUS:* **January 4, 1994**

NOTES FROM THE E.D.'S DESK

by Nick Gattuccio

'Tis The Season

A great deal in this issue of *Focus* concentrates on political matters. In that sense, it mirrors the season. It is no coincidence, after all, that there is heightened political activity on virtually all aspects of health care and medical research during the same season that President Clinton submitted his health care reform proposal to Congress and the American people.

Senator Mark Hatfield of Oregon, for example, introduced the Rare Disease Research Act of 1993, which will create an office of rare disease research at the National Institutes of Health (page 1). Meanwhile, Senator Tom Harkin of Iowa hopes to create a national trust fund for biomedical research that will double what this country spends on medical research (page 10). Although both appear quite far removed from the health care reform debate, this is not entirely true. In fact, Harkin's research trust fund is in some ways an attempt to force Clinton to find a place for biomedical research in the whirlpool of health care reform.

But Congress is not the only hotbed of political activity which sizzled into action this fall. By all accounts, contributions from health related agencies (insurance companies, HMOs, pharmaceutical manufacturers, medical societies, etc.) to the campaign coffers of senators and congressmen is at record levels, and by some estimates the line of lobbyists up on Capitol Hill runs half way to Baltimore.

In short, the health care game *will* change, and everyone and his brother's cousin with a stake in the game is angling for influence. The stakes are enormously high, after all.

What's In It For Us ...

President Clinton's Health Security Act offers the American people something which virtually every other industrialized nation in the world (except, I am told, South Africa) offers its citizenry—and which America, to its shame, has never before provided—universal coverage. Some would say this in itself is reason enough to offer enthusiastic support to the plan. Additionally, Clinton's plan offers portability of insurance. This means, if you change jobs, or if you lose you job, you don't lose out. The Clinton plan also eliminates exclusions for pre-existing conditions, which are devastating for people with genetic disorders. Clinton's plan also includes a basic benefits package which covers dermatologic diseases (although *which* dermatologic diseases is yet unclear).

In short, the plan is very much what President Clinton said it would be in his speech to the country in September: It is as much or more coverage for the same or less in premiums.

... and What's Not

There appear to be two greatest dangers to the ichthyosis community in the Clinton plan. One is the "Gatekeeper" principle; the other is the issue of "cosmetic" medical treatment.

Although the President's plan includes a fee-for-service option for those who wish to pay more to be free to elect any doctor they wish, the fact is, sharp economic pressures will force the majority of us to opt for the managed care plan, which is like an HMO. Under this system, all referrals to specialists would be channeled through a "primary care" physician (and in some cases non-physicians), known as the gatekeeper. Only with the gatekeeper's approval can a patient see a dermatologist. I don't need to explain to ichthyosis patients how ridiculous this would be.

The issue of treatments for ichthyosis being considered "cosmetic" (which would *not* be covered) is equally serious. The danger is that medical bureaucrats will judge ichthyosis to be a cosmetic disorder. The rationale is that because ichthyosis is incurable, and because it is seldom fatal (beyond infancy), treatments for ichthyosis are not technically therapeutic (and are therefore cosmetic). This is the judgement made by officials in the State of Oregon in the preparation of their basic benefits package, which excluded ichthyosis from medicaide coverage. This may become the toughest fight.

The most important things that we (and this includes you) can do are these: (1) stay informed, and (2) let your political leaders know your views. And remain abreast of developments in your state legislatures, too, because the Clinton plan will allow states a great deal of latitude in preparing their own programs.

BAY AREA PHARMACEUTICAL FIRM DEVELOPS ORPHAN DRUG FOR ICHTHYOSIS

The FDA grants orphan drug status to Cellegy Pharmaceuticals' product, Glylorin, which company officials hope will reach the marketplace in 1995

Cellegy Pharmaceuticals has yet to release a single product, and yet this Novato, California company is suddenly getting a lot of press. In fact, you may have seen the July issue of *Vogue* magazine, where an article (interestingly entitled "Beauty's New Frontier") gave significant play to this company, to its forthcoming products, and to the cutting edge of medical research which may offer help not just to ichthyosis patients, but to tired, aging skin as well.

Presently holding eight U.S. patents, with another five pending, Cellegy is poised to release (probably in 1995) the first new topical therapy for ichthyosis since Westwood released Lac-Hydrin in the early 80s. Called Glylorin (its trade name), the new product will be a prescription-strength topical treatment for several of the ichthyoses. Trials to date have established effectiveness with CIE, X-linked, EHK, and recessive lamellar ichthyosis. Earlier this year, FDA granted Cellegy Orphan Drug status for Glylorin. This is a special status available to manufacturers of drugs for rare "orphan" diseases affecting fewer than 200,000 people.

Evidence of Glylorin's importance to the ichthyosis community is that more than one member of F.I.R.S.T.'s Medical Advisory Board sits on Cellegy's Scientific Advisory Board—Dr. Peter Elias is its co-chairman, and Mary Williams is a member. The fact is, F.I.R.S.T. has been abreast of developments at Cellegy for some years, and we've been helping the firm find patients to participate clinical trials.

The person who discovered the importance of the class of compounds which lie at the core of Cellegy's research and development is Dr. Carl Thornfeldt, a clinical professor of dermatology at the Oregon Health Sciences University in Portland, Oregon. Dr. Thornfeldt is a co-founder of Cellegy.

Once he'd come upon this class of compounds, Dr. Thornfeldt turned to a noted expert in the area of skin biology which bears on lipid metabolism, Dr. Peter Elias of the UC San Francisco Medical School, and Director of the world renowned Dermatology Research Unit of the V.A. Medical Center in San Francisco. Cellegy is largely built upon this scientific collaboration.

What makes Glylorin particularly interesting is that it marks a departure from the past decade's mainstream in treatment strategies, most of them based on alpha-hydroxy acid products (lactic or glycolic). Glylorin is not based on the alpha-hydroxies. Furthermore, instead of focusing on the skin's keratin proteins, which are the most abundant proteins in the surface layer of the skin (i.e., scale), Glylorin's biochemical activity focuses on the skin's lipid metabolism.

The key to Glylorin's chemical action rests on the scientific conviction that the outermost layer of skin, the stratum corneum, is ***not*** just a barrier of dead cells (a commonly held view), but that instead it is an active, living structure that communicates and interacts with neighboring cells, organizes maintenance, and facilitates repairs of the skin's surface.

"Lipid metabolism provides a critical epidermal function," say Dr. Elias. "When the stratum corneum is disrupted, we have discovered how to orchestrate and manipulate... lipids to deliver dramatic improvements." Glylorin offers just such a manipulation.

Although Glylorin is Cellegy's entry into the realm of pharmaceuticals for dermatological use, the hope is that the line of research which led them to a treatment for ichthyosis will ultimately lead to an entire line of skin treatment products. As well as other treatment for skin diseases, these products will include over-the-counter preparations which fit in the expanding niche of products called "cosmeceuticals." On this latter front, Cellegy is evidently doing something right, because last year the Neutrogena Corporation paid Cellegy $5 million for about 20% of the company and marketing rights to some forthcoming over-the-counter products.

CELLEGY SEEKS PATIENTS FOR PHASE III CLINICAL TRIALS FOR GLYLORIN

Cellegy is presently planning for its entry into phase III clinical trials for Glylorin. Although trial sites are not yet set, it is known that a great many patients with several forms of ichthyosis will be needed at phase III trial sites around the country.

If you think you might wish to participate in these trials, and *if you know which type of ichthyosis you have*, you may contact officials at Cellegy to add your name to a roster of potential trial participants.

Contact Cynthia Selfridge at 415-382-6770.

THE DRUG DEVELOPMENT & APPROVAL PROCESS

By Dale E. Wierenga, Ph.D. and C. Robert Eaton
Office of Research & Development, Pharmaceutical Manufacturers Association

The U.S. system of new drug approvals is perhaps the most rigorous in the world. On average, it takes a company 12 years and $231 million to get one new medicine from laboratory to the pharmacist's shelf, according to a 1990 study conducted by the Center for the Study of Drug Development at Tufts University.

The flow chart (below) gives the success rate of drugs and the length of time each step takes. Overall, about one in five of the medicines that begins clinical testing makes it through the trials and the approval process. New medicines are developed as follows:

Preclinical Testing. A pharmaceutical company conducts laboratory and animal studies to show biological activity of the compound against the targeted disease, and the compound is evaluated for safety. These tests take approximately three and one-half years.

Investigational New Drug Application (IND). After completing preclinical testing, the company files an IND with the Food and Drug Administration (FDA) to begin testing the drug in people. The IND become effective if FDA does not disapprove it within 30 days. The IND shows results of previous experiments; how, where and by whom the new studies will be conducted; the chemical structure of the compound; how it is thought to work in the body; any toxic effects found in the animal studies; and how the compound is manufactured. In addition, the IND must be reviewed and approved by the Institutional Review Board where the studies will be conducted, and progress reports on clinical trials must be submitted at least annually to FDA.

Clinical Trials, Phase I. These tests take about a year and involve about 20 to 80 normal, healthy volunteers. The tests study a drug's safety profile, including the safe dosage range. The studies also determine how a drug is absorbed, distributed, metabolized and excreted, and the duration of its action.

Clinical Trials, Phase II. In this phase, controlled studies of approximately 100 to 300 volunteer patients (people with the disease for which the drug will be approved) assess the drug's effectiveness and take about two years.

Clinical Trials, Phase III. This phase lasts about three years and usually involves 1,000 to 3,000 patients in clinics and hospitals. Physicians monitor patients closely to determine efficacy [the extent to which the drug is effective] and identify adverse reactions.

New Drug Application (NDA). Following completion of all three phases of clinical trials, the company analyzes all of the data and files an NDA with FDA if the data successfully demonstrate safety and effectiveness. The NDA must contain all of the scientific data that the company has gathered. NDAs can run 100,000 pages or more. By law, FDA is allowed six months to review an NDA. In almost all cases, the period between the first submission of an NDA and final FDA approval exceeds that limit; the average NDA review time for new molecular entities approved in 1992 was 29.9 months.

Approval. Once the FDA approves the NDA, the new medicine becomes available for physicians to prescribe. The company must continue to submit periodic reports to FDA, including any cases of adverse reactions and appropriate quality-control records. For some medicines, FDA requires additional studies (Phase IV) to evaluate long-term effects.

Discovering and developing safe and effective new medicines is a long, difficult and expensive process. The research-based pharmaceutical industry will invest $12.6 billion in research and development this year, and that investment has been doubling every five years.

	Preclinical Testing	Clinical Trials			FDA Review		Phase IV
		Phase I	Phase II	Phase III			
Time	3.5 Years	1 Year	2 Years	3 Years	2.5 Years	12 Total	
Test Population	Laboratory and animal studies	20 to 80 healthy volunteers	100 to 300 patient volunteers	1,000 to 3,000 patient volunteers	New Drug Application (NDA) Review Process & Approval		Additional post-marketing testing required by FDA
Purpose	Assess safety and biological activity	Determine safety and dosage	Evaluate effectiveness; look for side effects	Verify effectiveness; monitor adverse reactions from long-term use			
Success Rate	5,000 compounds evaluated	5 compounds enter clinical trials			1 compound is approved		

BROTHERS & SISTERS OF SPECIAL NEEDS CHILDREN:

THE SIBLING STORY

by Carole Brown, Samara Goodman, and Lisa Küpper

Editor's Note: The following is excerpted from a comprehensive article entitled, The Unplanned Journey: When You Learn That Your Child Has a Disability, *which appeared in* NICHCY News Digest, *published by the National Information Center for Children and Youth with Disabilities, vol. 3, no. 1, 1993. The excerpt (and resources, which follow) is reprinted here by permission of NICHCY.*

We know from the experiences of families and the findings of research that having a child with a disability powerfully affects everyone in the family. This includes that child's brothers and sisters. Many authors and researchers have written with eloquence about how the presence of a disability affects each sibling individually, as well as the relationships between the siblings.

The impact, according to the siblings themselves, varies considerably from person to person. Yet there are common threads that run through their stories. For many, the experience is a positive, enriching one that teaches them to accept other people as they are. Some become deeply involved in helping parents care for the child with a disability, often assuming responsibilities beyond their years in terms of that individual's care and the maintenance of the household. It is not uncommon for siblings to become ardent protectors and supporters of their brother or sister with special needs, or to experience feelings of great joy in watching him or her achieve even the smallest gain in learning or development. Increased maturity, responsibility, altruism, tolerance, humanitarian concerns and careers, a sense of closeness in the family, self-confidence, and independence are among the other positive effects noted in siblings.

"Information, even concerning a painful subject, is preferable to ignorance distorted by imagination."

In contrast, many other siblings experience feelings of bitterness and resentment towards their parents or the brother or sister with a disability. They may feel jealous, neglected, or rejected as they watch most of their parents' energy, attention, money, and psychological support flow to the child with special needs.

The reaction and adjustment of siblings to a brother or sister with a disability may also vary depending upon their ages and developmental levels. The younger the

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F.I.R.S.T. WELCOMES OUR NEW BOARD OF MEDICAL EDITORS

F.I.R.S.T. this fall installed its first Board of Medical Editors composed of distinguished dermatologists and researchers from around the country. Drawn largely, but not entirely, from F.I.R.S.T.'s Medical Advisory Board, the Board of Medical Editors (BME) will fill an active role as F.I.R.S.T. moves forward aggressively with building our patient education and publications library (see related stories, p. 12).

The mandate will be broad. They will review medically related articles set for publication in *Focus*. They will help the editor get other physicians and researchers to write for the lay community in Focus and elsewhere. They will also review manuscripts of F.I.R.S.T. publications, pamphlets and other material that are set for general circulation. And finally, they will contribute on a rotating and team basis to our medical question-and-answer column.

All are distinguished members of the medical and biomedical research communities. All are actively engaged in research involving ichthyosis, and/or devote considerable energy in their clinical practice to ichthyosis. We are fortunate to have so distinguished an editorial board. Please join me in welcoming the following members:

BOARD OF MEDICAL EDITORS

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nondisabled sibling is, the more difficult it may be for him or her to understand the situation and to interpret events realistically. Younger children may be confused about the nature of the disability, including what caused it. They may feel that they themselves are to blame or may worry about "catching" the disability.

As siblings mature, their understanding of the disability matures as well, but new concerns may emerge. They may worry about the future of their brother or sister, about how their peers will react to their sibling, or about whether or not they themselves can pass the disability along to their own children.

Clearly, it is important for parents to take time time to talk openly about the child's disability with the family's other children, explaining it as best one can in terms that are appropriate to each child's developmental level. As Charles Callahan remarks, "Information, even concerning a painful subject, is preferable to ignorance distorted by imagination."

RESOURCES FOR PARENTS: SIBLINGS OF CHILDREN WITH SPECIAL NEEDS

BOOKS & ARTICLES

Ambler, L. (1988) "Children with disabilities: Understanding sibling issues." *NICHCY News Digest* (11), 1-12. [Available through NICHCY, PO Box 1429, Washington, DC 20012; (703) 893-6061; (800) 999-5599)]

Lobato, D. J. (1990) *Brothers, sisters, and special needs: Information and activities for helping young siblings of children with chronic illness and developmental disabilities.* Baltimore: Paul H. Brookes. [PO Box 10624, Baltimore, MD 21285 (800) 638-3775]

McCaffrey, F. D., & Fish, T. (1989) *Profiles of the other child: A sibling guide for parents.* Columbus, OH: Nisonger Center. [Publications Office, McCampbell Hall, Room 434, 1581 Dodd Drive, Columbus, OH 43210; (614) 292-8365]

Powell, T. &. P. A. Gallagher (1993). *Brothers and sisters: A special part of exceptional families* (2nd ed.). Baltimore: Paul H. Brookes. [PO Box 10624, Baltimore, MD 21285 (800) 638-3775]

MAGAZINES & NEWSLETTERS

Sibling Information Network Newsletter -- Sibling Information Network, A.J. Pappanikou Center, 1776 Ellington Road, South Windsor, CT 06074; (203) 648-1205. Published 4 times a year. For members, $8.50.

NASP Newsletter -- National Association of Sibling Programs, Sibling Support Project, Children's Hospital and Medical Center, PO Box 5371, CL-09, Seattle, WA 98105; (206) 368-4911

Exceptional Children -- Council for Exceptional Children, 1920 Association Drive, Reston, VA 22091; (703) 620-3660. Published 6 times per year. Nonmembers, $45; members, $14.

Families & Disability Newsletter -- Beach Cetner on Families & Disability, Bureau of Child Research, Univ. of Kansas, 3111 Haworth Hall, Lawrence, KS 66045; (913) 864-7600. Published 3 times per year; free.

NICHCY News Digest-- NICHCY, PO Box 1429, Washington, DC 20012; (703) 893-6061; (800) 999-5599)]

A SPECIAL QUESTION FROM PARENTS OF A SPECIAL CHILD

I had a letter recently from Donna Rice, our Region Six Coordinator and mother of young Haley Rice. You may recall reading in the summer edition of *Focus* (our special National Conference edition) about Haley's difficulties with nutrition and thriving. Through the summer, Haley's condition became quite serious This fall she underwent surgery to implant a gastrointestinal tube to facilitate feeding.

Donna's problem and her question regard anchoring the I.V. line to Haley's ichthyotic skin. I'll let Donna tell the story:

"Finding a vein that will accept an I.V. is difficult for the technicians and torturous for Haley. Then, it has been impossible to find a tape that will securely anchor the I.V. so it will not work its way out of the vein, while at the same time it will not damage Haley's skin. During one of Haley's hospitalizations in 1992 it was not unusual for a new I.V. to be inserted 5 to 7 times in a 24 hour period. I'm sure you can imagine the physical and emotional toll this takes on Haley (and her parents). Due to the lack of solutions with this problem, when I.V. treatment is now required, it has become necessary to surgically implant a line in the main artery to Haley's heart. This is obviously an imperfect solution. Not only does the surgery require general anesthetic, but the risk of infection is very high, and the introduction of an infection at this site is life threatening."

With this for background, Donna's question is this: "Have other F.I.R.S.T. members experienced difficulty with the insertion and anchoring of I.V.s? If so, has anyone been successful in finding a tape or other product that secures an I.V. without damaging the skin?"

If anyone has experience with this problem, Donna would very much appreciate hearing from you. You may call her at her home in Katy, Texas, at **713-391-4407.**

CREATIVE GIVING:

A REPORT FROM F.I.R.S.T.'S FOUNDATION DEVELOPMENT COMMITTEE

F.I.R.S.T. Launches 1994 Planned Giving Campaign

by Pamela L. Stockton
Board of Directors & Chair of F.I.R.S.T.'s Foundation Development Committee

Charitable giving has become one of the "hot" topics in estate planning circles. It is possible, now, to take advantage of charitable giving techniques which result in true win-win opportunities for both donor and charity.

What if someone told you that you can give an asset away, then use income from the sale of the asset without paying taxes on its sale, and *then* receive tax deductions and, by using another "vehicle," not lose the original asset's value in your estate? Would you think the person were insane? Well, there's more. You can also benefit your favorite charitable cause and still "feel" your donation during your lifetime. This "vehicle" is available today. It is called a *Charitable Remainder Trust*, with a *Wealth Replacement Trust.*

Magnifying Charitable Gifts

Many people feel they cannot give enough to their favorite charity to make a truly significant difference. However, the truth is, one does not need to be wealthy to provide a substantial gift to a charity. There are ways to literally *magnify* a gift of a few hundred dollars into a gift of thousands.

One technique uses life insurance premiums to leverage a substantial gift. For example, a gift of from $100 to $500 per year over ten years can result in the charity ultimately receiving a gift of from anywhere from $50,000 to $400,000. The actual figures depend on the donor's age and health, but this is the best of all means for leveraging a major donation.

Major Giving Through Insurance

In fact, there are several ways to donate with insuranc. A donor can enjoy the satisfaction of making a major gift (for example, establish a permanent endowment, like a research endowment, bearing whomever's name the donor wishes), while the donor need only give the cost of the policy's premiums, which themselves are fully deductible. Here are a few examples of ways to give with insurance:

(1) Donate an existing policy. The donor enjoys a tax deduction based on IRS guidelines.

(2) Assign a policy's annual dividends to the charity and deduct the dividend payments as a charitable contribution.

(3) Donate term or group term policies. The premiums are deductible.

(4) Rather than being taxed on group term coverate that exceeds $50,000, donate the excess over this amount, which removes it from the donor's taxable income.

But by far the most popular technique is to buy a new policy, make the charity the policy's owner and beneficiary, and then deduct the premiums as a charitable contribution. This is the ideal scenario for both donor and charity alike. Not only can a donor make a donation of tens or hundreds of thousands of dollars for just hundreds of dollars per year, but if the donor changes his or her mind down the road and discontinues payment of premiums, the charity can elect any number of options, either continuing the policy themselves, adjusting its face value, or surrendering the policy altogether for its cash value. Regardless of the outcome, no one loses. It is a true win-win.

For more information about these or other planned giving programs, contact F.I.R.S.T.'s executive director at our toll free number in Raleigh.

RESOURCE FOR GRASSROOTS FUNDRAISING PROJECTS

Board Member Tom Buehler Will Help F.I.R.S.T. Members Plan and Execute Fund Raising Projects

If you think you would like to run a F.I.R.S.T. Grassroots Fundraiser like the LaBarbera's did in Florida, but you're not sure you have the skills or the energy to do it, please call F.I.R.S.T. board member Tom Buehler. Tom has experience himself running grassroots fundraising events and he'd be delighted to talk with you to offer advice and help you get your fund raiser off the ground. By all means, you should also call on the executive director, Nick Gattuccio. He can help provide you with any material or technical help you might need.

There is an endless array of possible approaches to grassroots fund raising. Everything from Bowl-A-Thons to yard or bake sales can succeed.

-- Call Tom Buehler at (414) 542-1044 --

GRASSROOTS

LaBarbera Fund Raiser

Continues from Page 1

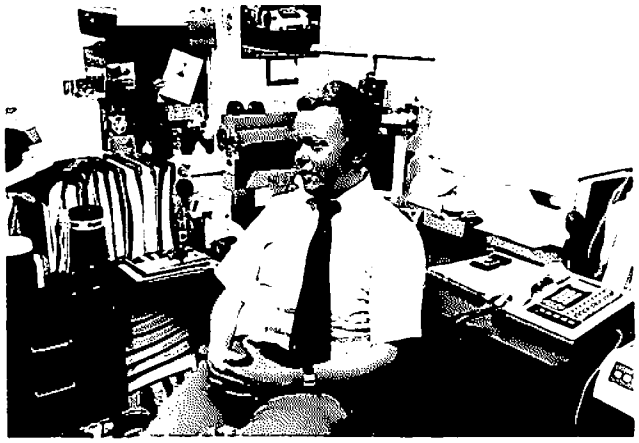
$2.00 (larger sums weren't refused). The fund raising events included a bake sale.

Scheduled to last just one week in May, the event took on a life of its own, and many of the LaBarberas own clients and industrial suppliers proved to be among the most generous donors. Among these were Windsor Industries, who donated for sale a piece of industrial equipment which then sold for $425. The company's representative, Mike Sargeant, supervised the donation. Also deserving special note are Randy, Joe and Chris LaBarbera themselves, who donated $350 to their own fund raiser, Anthony Consolino of Jackson, Michigan, who donated $300, and John Smith, the LaBarbera's CPA, who donated $200.

The bottom line for the LaBarbera fund raiser was $3,098.50! This is a stunning accomplishment—the most successful grassroots fundraiser in this Foundation's history.

All of us in the ichthyosis community owe Randy, Joe and Chris LaBarbera not just our hearty congratulations, but our esteem and our thanks as well. Efforts such as these keep F.I.R.S.T. afloat.

photo: Florida Times-Union © 1993



Randy LaBarbera in his office at All-Brite Sales in Ft. Lauderdayle, Florida

F.I.R.S.T. ELIGIBLE FOR 1994 COMBINED FEDERAL CAMPAIGN

C.F.C.

For the first time ever, F.I.R.S.T. has qualified for inclusion in the Combined Federal Campaign, a United Way type of giving program that is exclusively for federal employees (including the military).

The 1994 Campaign is presently underway, so all of you federal employees have the opportunity for the first time to identify F.I.R.S.T. as the recipient of your designated payroll donations.

Federal employees can find F.I.R.S.T. listed in your CFC Handbook in the section for "National Unaffiliated Organizations."

F.I.R.S.T.'s CFC listing number is 1061

U.S. AIR FORCE ACADEMY CADET TANYA LAND RUNS HER OWN CFC CAMPAIGN

Third-year Air Force Academy Cadet, Tanya Land, whose 2½ year old brother, Matthew, has lamellar ichthyosis, decided to head up her own private CFC campaign right there at the Air Force Academy in Colorado Springs. "F.I.R.S.T. has given me a great understanding of ichthyosis," says Tanya, "and I am more than happy to introduce F.I.R.S.T. to others. Now that F.I.R.S.T. is a CFC affiliate, I am introducing the organization to the cadet wing, and of course encouraging their support."

Tanya's parents are Lori and David Land, presently of Honolulu. Many of you may remember Lori as our former RSN Regional Coordinator for Region 6 when they lived in Texas.

"Why am I doing this? Because I love my little brother, Matthew, and because I care for those families and individuals who are in a similar situation."

Tanya is majoring in legal studies at the Academy. Upon graduation she hopes to attend law school at the University of Texas at Austin. We thank her sincerely for her work on our behalf.

A Five-Dollar Cancer Cure

By Senator Tom Harkin

It's hard to imagine a world where children are immunized against cancer before their second birthday, where Alzheimer's Disease is cured with a single shot, where AIDS can be taken care of in one visit to the doctor. But before Jonas Salk's discovery in 1952, most Americans couldn't imagine a polio vaccine, either. The fact is, while the health care debate has focused on cutting costs and expanding services, disease and disability continue to drive costs up.

Medical research is the key to eliminating diseases and making a health care system less costly and more effective. As part of any comprehensive reform package, we should establish a trust fund to guarantee increased research spending.

Last year, nine of the leading 10 causes of death among women were attributable to disease, as were seven of the top 10 among men. Heart disease and cancer, the two leading causes of death among Americans, will constitute one-fifth of America's expected $940 billion health care bill this year. Government health costs for Alzheimer's disease—which devastates four million Americans and costs $90 billion each year—are expected to increase dramatically as baby boomers get older. If we could discover cures, preventive measures and cost-effective treatments for any of these diseases, the long-term savings would be enormous.

Also, medical research has spawned the biotechnology industry, which by the year 2000 could be a $50 billion per year *American* enterprise. But this country will not remain the biotechnology leader if we do not invest more heavily in medical research.

Yet this year, 79 percent of all peer-reviewed medical research projects deemed worthy of funding by the National Institutes of Health will be turned down because of budget shortfalls. What's more, the President has taken a rob-Peter-to-pay-Paul approach for next year's proposed N.I.H. funding: AIDS and breast cancer research will get urgently needed increases but most other research will get cut, including heart disease, Alzheimer's and diabetes. [Since this article appeared, Congress restored most of these research funds which had been cut from the N.I.H. budget.]

While we don't know the exact outline of the reform package President Clinton will propose, it is likely there will be about 100 million health care policies covering all Americans and their families. A small portion of the cost of each policy should be set aside monthly in a medical research trust fund.

A monthly set-aside of $5 for each policy would put nearly $6 billion into the trust fund yearly and would allow for a 50 percent increase in medical research. Although this cost would likely be passed along to consumers, it is a small price to pay for the possibility of elimination cancer and other diseases. Congress would allocate money out of the trust fund for the National Institutes of Health.

Set-asides like this are common for social purposes. A small percentage of the cost of every airline ticket is set aside to assure air traffic safety and maintain runways and improve airports. The Public Health Service Act of 1970 that covers all national public health programs sets aside one percent of its Federal funds for research such as studying the effectiveness of treatment.

Studies have shown that every dollar invested in medical research can return up to $13

A medical research trust fund would more than pay for itself. Studies have shown that every dollar invested in medical research can return up to $13 in reduced worker absenteeism, improved productivity, and lower medical expenses.

The trust fund would likely have broad public support. A poll in December by the Alliance for Aging Research, a non-profit group in Washington, showed that 82 percent of the respondents think the health care reform debate should focus more on research. Last year, a Harris Poll showed that 91 percent favored increased investment in medical research.

Until we make this investment, the debate will largely be about paying bills, not preventing them, and long-term improvements in quality and cost reduction will be sacrificed to short-term fixes. Disease and disability ravage millions of Americans each year. We cannot afford to ignore the vast potential that medical research provides.

Tom Harkin (D-IA) is chairman of the Senate appropriations subcommittee that oversees funding for the National Institutes of Health. This article originally appeared in the *New York Times* (5/12/93) and is reprinted here with permission.

Senator Hatfield

(continued from Page 1)

ease research clinical database." This stated general purpose will involve a great many things, of course, and the Center's director will be asked to execute a broad mandate which includes: (1) conducting and supporting rare disease research; (2) disseminating information about rare diseases; (3) developing a central database on current clinical research projects for rare diseases; and (4) coordinating the conduct of rare disease research among all Institutes of the NIH and other Federal agencies.

Central to executing this mandate, the Director of the Center for Rare Disease Research will be required to develop a "comprehensive plan for the conduct and support of research on rare diseases." This "Strategic Research Plan," as it is called, will require the Director to devote considerable energy to not just raising the profile of rare disease research, but actively seeking means for promoting research on rare diseases. The Director will coordinate research that is conducted by various arms of the federal government, its agencies, and private entities, and will help raise the profile of research areas that have received little attention.

The Director will also be asked to determine such things as the need for registries of research subjects or for epidemiological studies of rare disease populations. He will identify obstacles to developing treatments for rare diseases, and will examine training and education for physicians treating rare diseases.

In short, this is a comprehensive law that will for the first time lend a coordinated hand to the conduct of rare disease research.

The law also creates a national Advisory Board on Rare Disease Research. The Advisory Board will "review and assess Federal research needs, priorities, activities, funding and findings regarding rare diseases." It will be composed of 15 individuals appointed by the Director of NIH. Of these 15, eight will represent the health and scientific disciplines, and seven will represent the interests of individuals with rare diseases.

Perhaps most interesting of the law's provisions is the requirement that the Center establish a rare disease clinical and informational database. The purpose of this will be to identify sites where research on rare diseases is being carried out. This is needed to ensure the exchange of information, to connect researchers with rare disease patient populations who may be willing to serve in studies or trials, and to connect patients with support groups and other support resources.

Senator Hatfield's is a landmark effort to bring some coordination to widely scattered and frequently obscure rare disease research efforts.

The bill has been referred to the Senate Labor & Human Resources Committee. At this writing, Senator Hatfield is actively seeking co-sponsors for the bill, as well as seeking an author for a companion bill in the House.

We encourage you to write to Senator Hatfield to congratulate him on his effort. We also encourage you to write your own Senators and Representative to express your support of this important legislation.

POSTSCRIPT: NOTES ON THE HARKIN INITIATIVE

Aides to Senator Harkins say the research trust fund can be viewed as an attempt to force the President to include provisions for biomedical research in his health care reform package, which presently emphasizes the delivery side of the health care reform at the expense of research. As presented in a press release issued from Senator Harkins' office, "Senators Tom Harkin and Mark Hatfield call on president Clinton to make medical research a core element of any health care package he sends to Congress."

Says Senator Harkin, "Without question, medical research is key to eliminating disease and making a health care system less costly and more effective. As part of any comprehensive health care reform package, we should establish a trust fund to guarantee increased research spending."

Incidentally, Senator Mark O. Hatfield is the ranking republican on the Senate appropriations subcommittee which Senator Harkins chairs (i.e., the subcommittee which oversees funding of NIH), and is a co-sponsor and active champion of the research trust fund legislation.

More than 200 medical and health organizations nationwide (including F.I.R.S.T.) have endorsed the Harkins/Hatfield plan for a research trust fund.

PATIENT EDUCATION & PUBLICATION FUND

At the latest meeting of the board of directors, held on September 26th, the board unanimously adopted a resolution to create the F.I.R.S.T. Patient Education & Publication Fund. This new Education Fund will act as a repository for *restricted* funds earmarked exclusively to pay for the publication of patient education books and pamphlets.

A restricted fund (like a special bank account) is a new departure for F.I.R.S.T. In the past, everything F.I.R.S.T. spent came out of the general operating budget. This has always limited our ability to take on special projects that might push spending over budget limits.

With a restricted fund, however, the budget is not a problem. How it works is this. The special fund is set up, and your board of directors and executive director seek out special donations—ideally, large grants from private foundations or corporations, or special bequests which the donor wishes to apply exclusively to the Education Fund. Then, as the Fund grows, we'll have the freedom to apply the Fund's assets to education and publication projects as we see the need without worrying about the budget.

"The Education Fund shall be permanently restricted to supporting bona fide educational publications."

The board's resolution, which is the Fund's chartering document, places several strict limits on the Fund's assets in order to guarantee that the money is spent on what we say it will be spent on. In the words of the resolution, "the Fund shall be permanently restricted to supporting production, publication, distribution and development costs for bona fide educational publications and other media." This might include an educational video tape down the road.

Publishing educational materials is an expensive proposition. F.I.R.S.T. has led the way in developing such material, but our efforts remain unpublished due to lack of funds. For example, many of you have probably heard about two publications which are presently in advanced stages of completion — a special handbook for parents of children with ichthyosis, and a handbook for teachers of children with ichthyosis. (See article below for description of both.) Both manuscripts are ready to go, and have been for nearly a year. So what's holding them back?

Funding. Each will cost between $7,500 and $9,500 to produce in press runs of 3000, and we have never had enough free money in the operating budget to pay these sums of money. We hope the Education Fund will allow these and many other educational projects to go forward.

We all know that F.I.R.S.T. is the ***only*** source of patient-directed literature about ichthyosis. Creating this new Education Fund is a step which acknowledges this side of F.I.R.S.T.'s mission. In fact, we hope over the coming years to develop an entire library of educational material for the ichthyosis community — and not just for patients and their parents, but for other professionals as well. The Teacher's Manual is just the beginning on this front. *(See the article below for an outline of what we hope this library might look like a few years down the road.)*

THE PATIENT EDUCATION LIBRARY

The executive director has developed a list of titles upon which to build the first phase of F.I.R.S.T.'s Patient Education Library. Heading off the list, and at the top of our present priority list, are two titles which are virtually ready to go, awaiting only funding. Following these are titles of projects that are either just recently underway, or else are on the drawing board. This is a long-term plan (three to five years).

Complete Manuscripts (for 1994)

(1) *Handbook for Parents of Children with Ichthyosis.* This is a substantial manuscript (about 12,000 words, or roughly 50 pages) divided into six sections and focusing on three areas: (a) introduces the medical/clinical aspects of chronic disease and seeks to demystify relationships with medical professionals while creating a comfort zone amid an array of complex medical information; (b) provides a comprehensive survey of caregiving fundamentals, including discussions of topical and systemic therapies, as well as related information ranging from nutrition to climate; and (c) treats secondary issues, both personal and developmental, ranging from the financial to the psychosocial dimensions of parenting a special needs child.

(2) *Handbook for Teachers of Children with Ichthyosis.* This is also a substantial manuscript (about 8,000 words, or roughly 35 pages) which covers four primary areas: (a) definition and intro-

BOARD TAKES STEPS TO ENCOURAGE VOLUNTEERS

Board of Directors Creates Ad Hoc Committees to the Standing Committees of the Board to Allow Non-Board Members to Participate in F.I.R.S.T.

The board of directors enacted at the September 26th board meeting a resolution creating "Ad Hoc Assisting Committees to the Standing Committees of the Board." The resolution's sponsor, board member Cynnie Bates, felt strongly that F.I.R.S.T. needed to create opportunities for non-board members to participate in the policy-making and decision-making structure of F.I.R.S.T.

The resolution states that the chairpersons of each of the board's standing committees (see sidebar) are authorized to create ad hoc committees made up of non-board members of F.I.R.S.T. The members of the ad hoc committees shall be appointed by the respective committee chairpersons, and will work at their direction.

The purpose of the ad hoc committees will be to assist their respective standing committees in performing their duties and responsibilities. It is hoped that this will provide F.I.R.S.T. members who have the desire with an opportunity to take part in the inner workings of the Foundation. Although members of the ad hoc committees will have no vote on the board of directors nor on the standing committees themselves, service on the ad hoc committees should prove to be a great opportunity to take a more active role, have your opinions heard, and get your ideas listened to.

Those interested in serving on an ad hoc assisting committee should contact the chairperson of the standing committee which most interests you. To the right is a list of the board's standing committees, a brief description of their responsibilities, and the name and home phone number of the chairperson for each. (Incidentally, the board's executive committee is the single exception to the new program.

STANDING COMMITTEES OF F.I.R.S.T.'s BOARD OF DIRECTORS

Foundation Development Committee
Oversees fund raising activities. Coordinates fund raising policies and programs; establishes strategies, policies, and coordinates the efforts of the board and staff to ensure the fiscal stability of the foundation. Chair: Pamela Stockton, 919-781-6246.

Finance Committee
Oversees fiscal activities and coordinates fiscal policy. Monitors cash flow, provides periodic financial reports, and studies and recommends short- and long-term investment strategies. Chair: Georg'Ellen Betts, 919-848-0166.

Personnel Committee
Monitors performance standards for executive director and for board of directors. Develops means of evaluation, conducts evaluations on a timely basis, and periodically reviews and revises position descriptions and employment documents. Chair: Frances McHugh, 609-461-3766

(Continues on Page 14)

duction to the clinical features of various types of ichthyosis; (b) treatment fundamentals and key danger signs; (c) developmental and psychosocial implications of ichthyosis, broken down by age group; and (d) comprehensive bibliography of resources for teachers and students. The intended purpose of this book is to give parents a useful tool when they encounter their child's most difficult transition from home to school.

Projects in Development (1994-97)

(1) An encyclopedic glossary of medical and pharmaceutical terms for the ichthyosis patient. In addition to formal definitions of terms, will provide descriptive illustrations of usage. Designed to allow the lay person to consult full range of ichthyosis-related medical literature, evaluate medical records in an informed manner, and consult knowledgeably with attending physicians.

(2) *The ABCs of Topical & Systemic Treatments for Ichthyosis.* Intended as a comprehensive guide to help parents and patients navigate the complex array of available treatment products and strategies. Will include a primer on classes of compounds commonly found in topical products, and, for prescription products, key information from clinical trials.

(3) An extensive reprint series to make available medically-related articles drawn from twelve years of *Ichthyosis Focus.*

(4) A series of detailed fact sheets on each of the "relates skin types" commonly classified among the ichthyoses.

Many other projects are also under consideration or underway. If you have ideas, please let us know.

N.O.R.D. REPORT

The National Organization for Rare Disorders (NORD) is an umbrella organization representing the interests of groups like F.I.R.S.T. in the difficult arenas of political lobbying and health-care advocacy."N.O.R.D. Report" is an ongoing digest of highlights from NORD's newsletter, NORD ON-LINE.

Observations About Health Care Reform, Part 1 (Department of Quotable Quotes):

"In 1968 there were an average of 3.16 patients for every hospital administrator, while currently there are 1.43 administrators for every patient." (*New England Journal of Medicine*)

"Government must demonstrate it can do things. If government cannot do something for its children, it's not much of a government as far as I'm concerned." (HHS Secretary Donna Shalala)

"Your family has a lot at stake in health reform. Make sure you let your Senators and Representative know what you think. The insurance companies and drug companies can outspend us, but we can outnumber them! (Ron Pollack, Executive director, Families USA)

"If we'd only had the good sense to charge for all the copies of the draft [health care reform] plan that are all over town, we probably would have solved all the financing problems." (Ira Magaziner, after a copy of Clinton's health care reform plan was leaked to the press)

Observations About Health Care Reform, Part 2 (The Way of All Flesh):

Citizen Action reports that the first seven months of this year saw the highest level of contributions ever from the health and insurance industries to the campaign coffers of Congressmen and Senators. Pharmaceutical corporations and medical products manufacturers increased contributions 33%; hospitals, HMOs and nursing homes increased 31%. The top three contributors during the seven month period were the American Medical Association, National Association of Life Underwriters, and the American Hospital Association.

Health & The Economy

U.S. Census Bureau data on the 1990-91 recession indicates it was harsh on all sectors of the economy except the "health services sector." While revenues for most other sectors of the economy ran to negative numbers during this period, nursing home revenues increased by 9% while nonprofit hospitals increased revenues by 11%.

New Director at NIH

President Clinton recently appointed Harold E. Varmus as new Director of NIH, succeeding Dr. Bernadine Healy. Dr. Varmus is a Nobel Prize winning microbiologist from the University of California, San Francisco. He is a basic scientist who has long been known to vocally oppose political influence on scientific research. Most recently, Dr. Varmus opposed creation of an NIH Office for AIDS Research, and warned that NIH is becoming a "political battleground among disease interest groups." He won the Nobel Prize in 1989 for discovering oncogenes which cause cancer.

In The Wake of Dr. Bernadine Healy

When Dr. Bernadine Healy left the directorship of NIH, there was an apparent sigh of relief. In an August article critiquing NIH, the journal *Science* describes NIH as a bloated agency where scientific fiefdoms squelch innovative research. The institute directors did not like Dr. Healy and, according to the article, felt they did not have to answer to her. She had accused the in-house laboratory personnel of being "positively dictatorial." They, in turn, have described Dr. Healy's administration as hostile and defensive.

Dr. Healy has announced her intention to run on the Republican ticket next year for an Ohio Senate seat.

Standing Committees
(continued from Page 13)

Strategic Planning Committee
Oversees and coordinates Foundation's long-range planning in a fashion consistent with its mission, philosophy and goals. Will attempt to have a long-range strategic plan in place in 1994. Will initiate biennial reviews of strategic planning document. No chair at present -- you may contact the executive director.

Nominating Committee
Coordinates recruitment of new members of the board of directors. Determines goals and needs in board recruitment; targets and solicits interested new members; develops application and review procedure for prospective members; implements system for evaluating prospective applicants. Chair: Deb Vilas, 212-427-5904.

Communication Committee
Oversees the Foundation's public relations, public information, education, and marketing efforts. Includes assisting with developing promotional material, formal public relations efforts, publication production, and other related activities. Chair: Ginna Frantz, 212-687-0564.

NOTE:

NEW ADDRESS FOR R.S.N. COORDINATOR

Heather Gattuccio, RSN Coordinator (and husband Nick, too, for that matter) moved recently and have a new address and phone number. Please make a note of it:

3726 Bellevue Road
Raleigh, NC 27609

919-781-6671

NEWS & NOTES

New Brochure for Participants in Genetic Research Studies

The Alliance of Genetic Support Groups, an organization of which F.I.R.S.T. is a member, has recently published a very informative new brochure entitled "INFORMED CONSENT: PARTICIPATION IN GENETIC RESEARCH STUDIES." The brochure defines what constitutes genetic research, explains the term "informed consent," describes some of the risks which participating in genetic research may entail, and then presents a question-and-answer section which anticipates many question which might arise.

A great many members of F.I.R.S.T. have participated in one or more of the important genetic research projects presently underway at several sites in the United States. Furthermore, F.I.R.S.T. occasionally helps researchers contact patients to participate in genetic research. If you are considering participating, you may wish to have this brochure. Contact the Alliance of Genetic Support Groups at 35 Wisconsin Circle, Suite 440, Chevy Chase, MD 20815; or call 800-336-GENE or 301-652-5553.

Books for Children With Medical Conditions

Magination Press (19 Union Square West, New York, NY 10003) publishes books about medical conditions for children from 4-8 years old. Here are a few of their latest titles.

Little Tree: A Story for Children with Serious Medical Problems, by Joyce C. Mills, a therapist who tells stories as a healing process. Little Tree loses branches in a storm. Exams, surgery, setting of bones, grafting and emotions such as fear, self-blame and worry are described. Little Tree is comforted to learn that "she still has deep roots, a strong trunk and a beautiful heart."

What About Me? When Brothers and Sisters Get Sick, by Allan Peterkin, a psychiatrist at Montreal Children's Hospital. A girl who worries about her hospitalized brother but also feels jealous of the attention he gets shows the ways she attempts to cope. Her parents are distracted but finally realize she needs their help as well.

The United Way Dilemma

Many of you elect to give to F.I.R.S.T. through your local United Way drive at work. Others of you know that this is not always possible. Because F.I.R.S.T. is not formally a member of United Way, it is up to the local UW agency in your area whether or not they will honor your designation of F.I.R.S.T. as the recipient of your donation. Many honor this request, but some do not.

Furthermore, when we receive your donations from local UW agencies, they come as lump payments, and we do not in all cases know from whom the money came. Furthermore, these UW checks usually represent just a part of the annual pledge (they come in installments over the year), so they aren't the same size as your pledge. Furthermore, administrative costs have been subtracted by UW.

The bottom line is this: In order for us to accurately credit you for your United Way donations, ***please let us know in advance about your pledge.*** Please drop us a note and tell us your name, your employer, the amount of your pledge, and the name and phone number of the local UW agency which is conducting the drive.

To those of you who have donated through UW in the past and who have not been acknowledged or thanked by us as you should have been, please forgive our apparent bad manners. Please understand that the fault may not be entirely ours. We may not have received your donation at all, or else it may have come "anonymously." United Way is an agency with which is sometimes difficult for us to work.

Letter From A Friend

"The enclosed check for $100.00 is a contribution from my daughter, Julie Cohan, in honor of her sister, Christy Cohan. Christy was born in 1982 with lamellar ichthyosis.

"I would like to share with you the story behind this contribution. Julie graduated from Purdue University in May of this year. She graduated with a degree in Industrial Engineering and with honors. However, there was a period during her sophomore year when she had doubts about her choice of majors. The subject matter was difficult, study hours long, and her grades not the best. She persevered and at the same time vowed that if she did graduate without changing her major, she would contribute $100.00 to a charity as a means of celebration.

"I was quite touched when she took a few moments to write me a check on that busy graduation day. Julie started a job with Saturn in Spring Hill, Tennessee, in July as an industrial engineer. Needless to say, her father and I are very proud of her, and with pride I forward this check to you."

— Pamela G. Cohan
Birmingham, Alabama

NEW CANADIAN REGION OF THE R.S.N. STARTING UP IN ONTARIO, CANADA

Barbara Rockwell of Mississauga, Ontario, Canada has volunteered to head up of the Regional Support Network expansion into Canada.

Canadian representation on our membership rolls continues to grow, and we've been struggling to meet the new demands. Barbara's energy and enthusiasm will go far toward bringing us all together across our border.

Barbara has Netherton's Syndrome. She's a long-time member of F.I.R.S.T., and lives with her husband, Dave and their children. We all met and shared our experiences at the national conference in Chicago last June. Barbara wants everyone to know they are not alone with their ichthyosis, even in the distant reaches of our northern neighbor.

Our Canadian friends who are interested in becoming members of the RSN should please contact Barbara:

3080 Ballydown Crescent
Mississauga, Ontario L5C 2C8

416-896-9620

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Regional Support Network

The Regional Support Network facilitates communication between members of the ichthyosis community. Parents can exchange practical tips and child-care information. Adults can support one another by sharing experiences in job hunting, self-treatment, medical issues, social coping strategies, and other issues. If you wish to join the support group in your area, please contact the representative for your region. ***If you wish to join your area's Network, call your Regional Coordinator or F.I.R.S.T.'s toll-free number to receive your registration form.***

REGION ONE
NY, PA, VT, NH, NJ, CT, RI, MA, ME
Deb Vilas
7 East 88th Street, #4-B
New York, NY 10128
(212) 427-5904

REGION TWO
DE, MD, WV, VA, NC, SC
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Route 1, Box 189-F
Sandy Ridge, NC 27046
(919) 871-3277

REGION THREE
TN, GA, FL, AL, MS, LA, AR
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(416) 896-9620

NETHERTON'S SUPPORT GROUP
Cathy Sipper
P.O. Box 127
Rutledge, AL 36071
(205) 335-6827

Y E S !

I Want To Help F.I.R.S.T. Help Others In The Fight Against Ichthyosis

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