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

ICHTHYOSIS FOCUS

Vol. 14, No. 2 A Quarterly Journal for Friends of F.I.R.S.T. Spring 1995

The 1995 National Family Conference in San Diego is rapidly becoming an international conference. So far, delegations are slated to arrive from Mexico City, The Netherlands, Bermuda, and from England.

Not Too Late To Register for National Family Conference 1995 in San Diego

The Conference Program is 90% in place, and our Faculty" is Set

To make certain everyone has an opportunity to attend our upcoming 1995 National Family Conference in San Diego, we've pushed the registration deadline back so that those receiving this issue of *Focus* can still have time to register.

We're looking forward to an exceptional National Conference this year. The goal is attendance of 400, and so far we're well on the way to that.

The conference program will include general sessions and breakout workshops on a broad variety of topics. There will be a full program for teens and young adults, a workshop on retinoids, presentations on the new National Registry for Ichthyosis, gene therapy, new drug development, topical treatment strategies, a presentation by discoverers of the gene for lamellar ichthyosis, as well as popular "roundtable" special interest discussion groups and a panel. There will also be representatives from the pharmaceutical industry, and a great deal more, plus a Mexican Fiesta/ Reception on Friday, Banquet on Saturday, and a plenty of time to interact, teach, and learn from one another.

We look forward to seeing all of you at our 1995 Family Conference in San Diego.

Creative Ways to Get to San Diego

Families Draw on Local Resources for Funds to Attend the Conference

We've learned from families attending our San Diego National Family Conference that many creative ways can be found to fund the trip with local resources.

One family whose child has ichthyosis has obtained help from their school district. The school district is paying for conference registration fees and also helping to underwrite costs for traveling to San Diego and staying for three days.

Another family is receiving assistance from a local fraternal lodge (the Order of the Eagles) for assistance. The parents of this child with lamellar ichthyosis is a member of the local lodge, and the lodge has been a yearly contributor to F.I.R.S.T. for many years.

Other strategies include church groups, women's groups, and other benevolent organizations whose mission it is to serve those in need.

Anyone pursuing these avenues who needs our help developing a request, please call Nick at the office in Raleigh: 800-545-3286.

IN THIS ISSUE . . .

Ichthyosis Focus
Vol. 14, No. 2
Spring 1995

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is published quarterly by the Foundation for Ichthyosis & Related Skin Types (F.I.R.S.T.)

Anyone is free to reprint, with credit to F.I.R.S.T., material contained in *Ichthyosis Focus.*

P.O. Box 20921
Raleigh, NC 27619-0921
919-782-5728
800-545-3286
FAX: 919-781-0679

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

Dear F.I.R.S.T.,

It has been a while since I have written any letter to you, but over the years the membership has grown and I'm sure there are some new members that may be interested in my experience in controlling my X-linked ichthyosis.

I joined F.I.R.S.T. back in 1984 or '85 and attended the national conference in Chicago that year. I was 46 years old then and had suffered with ichthyosis all my life. I lived in New Jersey until 1990 and have always worked outdoors, so in the summer I would clear up, as sunshine will clear my scales, but only for about four months. I used sun lamps when I was younger, but they didn't do much for me. I even built my own tanning booth, but that didn't do much, except that I did finally develop some basal cell skin cancers, which I had removed.

I had all of the heartaches and embarrassment as a child that your readers describe. My biggest wish in life was that I wouldn't die with this damn skin. And your Chicago conference gave me my wish.

I went out there and Dr. Eugene Van Scott did a presentation about topical treatments that ended up changing my life. He introduced me to Aqua Glycolic lotion, and after about a month suddenly all of the scales on my legs loosened and started coming off. This was in January, the coldest time of year and no sunshine to help me along.

Well, I have been using Aqua Glycolic lotion for ten years now with complete success. Every day after I shower I rub myself down all over with the lotion and I am basically clear. In June, 1990, I moved to Florida, so along with the warmth and humidity down here I'm fine.

Please feel free to use my name, and if anyone would like to contact me for anything further about my experiences with X-linked ichthyosis, they may feel free to write.

Captain Joe Galluccio
245 N.E. Blairwood Trace
Jensen Beach, Florida 34957

Dear F.I.R.S.T.,

I was born in 1952 with ichthyosis. I was the only one in my family with it. My feelings of being alone and lonely grew as I did, and I guess I resented my brothers and sister for not having it, especially when the kids were so cruel at school.

Back then dermatologists didn't even know what the name of it was, much less how to treat it, so they told my mother to bathe me only once a week and they gave her some very strong smelling lotions to apply twice a day. My school life was hell! Since then I found bathing every day and using petroleum jelly works a lot better.

I was married and gave birth to three children, all with ichthyosis. I have a tremendous amount of guilt about that. I have been divorced for about twelve years now and pretty much keep to myself. I don't have friends because I got hurt so much through my childhood and teenage years that it's so much easier to live this way.

I try to help my kids at school by talking

F.I.R.S.T. CAN NOW BE REACHED ON-LINE VIA COMPUSERVE

`Our CompuServe address: 74722,1571`

`You may also reach us over the INTERNET by addressing email this way:` **`first@74722.1527.compuserve.com`**

Deadline for submissions to the next issue of FOCUS: August 1, 1995 to the other children's parents and the teachers, so life hasn't been as hard for my kids as it was for me. They, however, have chosen to pretend they don't have anything wrong with them, and they won't really talk about it to me or anyone.

I would like to hear from anyone who has ichthyosis. I would love to hear suggestions about skin care, and I would also love pen pals, male or female, who also have ichthyosis.

Sheryl Gorecki
915 16th Street
Ely, Nevada 89301

Dear Mr. Gattuccio,

I want to extend our heartfelt thanks to you for all of the wonderful information and time spent over the phone with our nurse when our son A.J. DelGrande was born at Memorial Hospital in Colorado Springs in March of this year. It was quite comforting to know that someone out there cares and had useful information to guide us.

A.J. is doing really well. He has lamellar ichthyosis, but has had no complications other than heat intolerance during very hot weather.

Thanks again for all you've done. Sincerely,

Angela & Mark DelGrande
Colorado Springs, Colorado

Dear F.I.R.S.T.,

My name is Laura Ashton and I live in Bermuda. I am 9 years old, and I am wondering if there are going to be any other girls or boys my age who are going to be at the Conference in San Diego this June.

I am interested in the children in Sweden with ichthyosis who want pen pals. I would like to find one my age and who maybe has my type of ichthyosis (lamellar).

I like to read "Baby-Sitters Club" books and "Goosebumps" books. I go to Bermuda High School for girls, and I am in grade 4 in Mrs. Briget Jardines class. I am an only child, and I live with my parents in Saltashe Cottage. My birthday is on November 3rd.

Laura Ashton (age 9)
P.O. Box P.G. 201
Paget PGBX / Bermuda

Laura: Yes, there are children your age coming to the conference in San Diego, and we very much look forward to seeing you there. We have some very special activities planned for our young people, and I think you'll find the conference a lot of fun. To connect with a pen pal with ichthyosis in Sweden, write to the following —ed.

Agneta Ganemo, Secretary
Iktyosforeningen
Ganarp 2517
260 80 Munka Ljungby
Sweden

Dear F.I.R.S.T.,

Thank you for all of the wonderful work you are doing for people with ichthyosis. I am an adult with ichthyosis vulgaris, and my two children, ages 10 and 5, also have this condition.

We would greatly appreciate hearing other people's experiences with ichthyosis vulgaris. I'm surprised not to see much information or many letters about our condition in the newsletter. I realize we have the so-called "mildest" form of ichthyosis, but to me it is still quite a disfiguring condition.

If you have any advice on treatment options or just some moral support from others with this condition, it would be a great help to me and my family.

Carol O'Connell
West Kill, New York

Carol: You make an excellent point. We try hard to include all of our members, and address issues facing everyone. Every form of ichthyosis is serious for the person who has it, and we try to bring this philosophy to the pages of Focus.

We invite all of our members with ichthyosis vulgaris to share with all of us your experiences living with and treating this disorder. We'd be especially interested to know about treatment products or regimens that you've found especially useful. —ed.

Dear F.I.R.S.T.,

We are sending this donation in honor of our grandson, Ethan Joyce, son of Darrell and Robin Joyce. We think F.I.R.S.T. has been a help to them. Ethan is such a joy to us. He is so outgoing. If you are having a bad day and Ethan comes, he makes you feel better. He has had so many prayers going out for him. He is a great blessing to us.

John & Margie Joyce
Sandy Ridge, North Carolina

PRESIDENT'S LETTER

by Deborah B. Vilas

It has been a busy Spring so far for the Foundation. As plans are laid for our upcoming National Conference in San Diego, the Board has been hard at work with myriad activities.

To start with, I had the pleasure of accompanying our Executive Director to New Orleans in early February to represent F.I.R.S.T. at the annual meeting of the American Academy of Dermatology. We staffed a F.I.R.S.T. exhibit booth and shared a lot of information and literature with physicians attending the conference from all over the world.

We also convened a meeting of F.I.R.S.T.'s Medical Advisory Board, and attended the annual Winter meeting with representatives from the Coalition of Patient Advocates for Skin Disease Research (CPA-SDR). At these meetings we had the opportunity to report on the progress of our organization, and receive updates from the medical, political and research fronts.

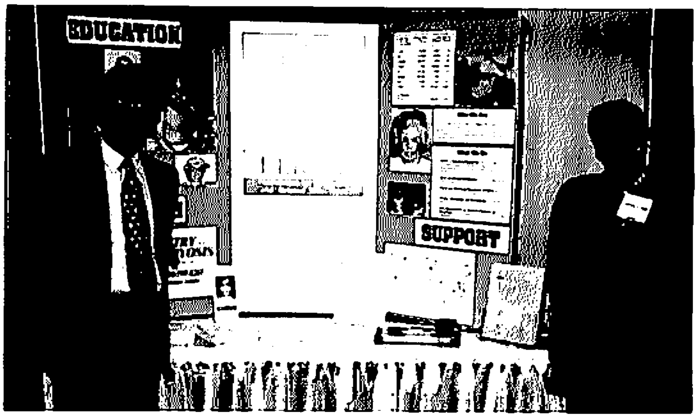
Your Board has also been busy this Spring. The Board's Personnel Committee has been hard at work completing the yearly performance evaluation of our executive director. We are pleased to report that Nick Gattuccio was recognized for his ongoing dedication and excellent work on behalf of our fast growing organization. Under his management, we reached several monumental goals in 1994, including the realization of our dream for a national patient registry, and the publication of our long awaited Parent's Handbook and Teacher's Manual.

The Board's Nominating committee has sought to develop the Board by striving to balance the appointment of specialized Board members (those with legal, financial and development expertise, for example), with Board members who are personally involved with ichthyosis. We rely on the latter for focus and the deep commitment that comes from individuals with a deep personal connection with ichthyosis. We are happy to report that we have succeeded in reaching this goal, as our Board is currently a rich balance of talents and energy from both realms.

Finally, the Board's Strategic Planning Committee will be meeting at the end of April to examine the long term mission and goals of the Foundation. I look forward to reporting their findings to you in a future President's letter.

Until then, may this letter find you well. I hope to see many of you in San Diego. Best Wishes,

Deborah B. Vilas



Executive Director Nick Gattuccio (l) and Board President Deborah Vilas stand before F.I.R.S.T.'s exhibit booth at the 1995 annual meeting of the American Academy of Dermatology in New Orleans. This year's convention brought together about 13,000 dermatologists, research scientists, pharmaceutical manufacturers, skin disease advocacy representatives, and others for eight days this past February.

SPECIAL SUMMER CAMP FOR CHILDREN WITH SKIN CONDITIONS

Camp Horizon — A Special Place for Special Kids

Camp Horizon, a new summer camp for children with skin disorders, will open this year. The camp session is planned for August 19-22, 1995, on a beautiful 35-acre campground near Millville, Pennsylvania.

Sponsored by the Department of Dermatology at the Geisinger Medical Center, Camp Horizon is set at Camp Victory, which is also home to camps for children with cancer, spina bifida, and organ transplants, and is fully developed with a medical facility, cabins, a dining hall, swimming pool, a pond for fishing and boating, and pavilions for recreational activities. The camp's professional staff includes experienced and trained counselors, volunteer dermatologists, a camp nurse and dermatology nurse. And, if necessary, the services of Geisinger's children's hospital are readily available.

All children with skin disease between (roughly) the ages of 8 and 13 are invited. No fee is charged for camp, and limited transportation scholarships are available for campers who need them.

Camp Director is Howard Pride, M.D., a dermatologist at the Geisinger Medical Center. For more information, call the Department of Dermatology at **717-271-8050.**

REGION FOUR CONFERENCE PLANNED FOR INDIANAPOLIS AUGUST 12th

by Cynnie Bates

Thanks to efforts by Jill and Mark Wood, our Region's second Regional Conference is set for Saturday, August 12, 1995, at the Indianapolis Marriott Hotel. We've also planned a side trip to the Indianapolis Children's Museum, the largest museum of its kind in the nation. The museum has five floors of fun for kids of all ages, even those of us who may have a grey hair or two.

Our Regional Conference will be quite different from the National Conference in San Diego this June. While the National Conference will offer a wealth of scientific information and the opportunity to hear and meet experts in the field as well as a fantastic array of individuals from around the country and elsewhere, our regional conference will be smaller (we anticipate about 150), and will be mainly social. The emphasis will be on meeting others, learning from shared experiences, and just having fun at the Children's Museum. No formal presentations by professionals are planned, although several professionals will be invited to join us for lunch and take time for one-to-one questions and answers shortly after.

We invite everyone to join us who finds the location and date of our Regional Conference convenient. Region Four Conference registration begins June 1 and extends through July 11.

If you would like further information, please call Region Four Coordinator Cynnie Bates at 606-276-0142, or Mark or Jill Wood at 317-841-9923. We'll be happy to hear from you.

Growth & Change in the Board of Directors

George'Ellen F. Betts Steps Down as Board Financial Officer Following Seven Years of Devoted Service; New Board Members Elected

We lost this year the devoted services F.I.R.S.T.'s Chief Financial Officer, Georg'Ellen F. Betts, who retired following seven years of exemplary service to F.I.R.S.T., the past four as CFO. Because she lives in Raleigh, near F.I.R.S.T. headquarters, her commitment to the Foundation always went far beyond her dedicated commitment to her Board responsibilities. She also was a dedicated volunteer at the office, doing everything from helping with the mail to managing day-to-day financial activity.

Georg'Ellen first became involved with F.I.R.S.T. when her daughter, Ellen Rowe, assumed the Board Presidency in 1987 and the Foundation's headquarters moved to Raleigh, NC. She was first elected to the Board of Directors in 1989, and served as CFO since 1991.

Georg'Ellen's impact on F.I.R.S.T. was significant during these years. A tireless advocate on behalf of ichthyosis patients and their families, she remained an unswerving trustee of the best interests of our membership throughout her tenure.

I'm sure that the entire membership joins in wish Georg'Ellen best wishes, and in offering sincere thanks for her tireless efforts over the years.

New Members Join F.I.R.S.T.'s Board of Directors

Four new members have joined F.I.R.S.T.'s Board of Directors over the past months. Filling Geoge'Ellen Betts' shoes as Chief Financial Officer is **Phyllis Edwards** of Raleigh, NC, an accountant with the firm of Ernst & Young. Phyllis has a special expertise in nonprofit financial management, and will add significantly to the Board's skill as stewards of the Foundation's resources.

Joining Phyllis is **Michael Dunleavy** of Philadelphia, PA. A vice president at the firm of Crown Cork & Seal in Philadelphia, Mike brings considerable business acumen, as well as experience in development and strategic planning. As the Foundation continues to grow and develop as a nonprofit organization, Mike will lend valuable expertise as we lay the foundation for the future.

Also joining the Board this winter is **Beth Peritz** of Baltimore, MD. Possessing both law and social work degrees, Beth brings a palette of useful talents and experience to the Board. During periods of growth and expansion, broad based skills such as Beth's will add immeasurably to the Board's ability to guide our development.

F.I.R.S.T.'s 1995 NATIONAL CONFERENCE
JUNE 16, 17 & 18 -- SAN DIEGO

Exceptional Faculty Slated For the 1995 National Family Conference

An exceptional faculty of health care, developmental and other professionals has volunteered to join us at our National Family Conference in San Diego this June. Following is a nearly complete roster of participants:

Leonard Milstone, M.D., Chairman of F.I.R.S.T.'s Medical Advisory Board, prominent researcher, and professor of dermatology at the Yale University School of Medicine. He has a special interest in future trends in ichthyosis research and therapy, including possible opportunities for gene therapy.

Philip Fleckman, M.D., member of F.I.R.S.T.'s Medical Advisory Board, Director of the recently developed National Registry for Ichthyosis and Related Disorders, researcher, and professor of dermatology at the University of Washington School of Medicine in Seattle. Dr. Fleckman will discuss the Ichthyosis Registry, its importance to us, and its role for the future of research in the ichthyoses.

John DiGiovanna, M.D., Director of the Clinical Research Unit of the Laboratory of Skin Biology, National Institute of Arthritis and Musculoskeletal and Skin Diseases at the National Institutes of Health. Dr. DiGiovanna has a special expertise in the retinoids, and is part of the NIH team which located the site of the gene for lamellar ichthyosis this year.

Sherri J. Bale, Ph.D., Director of the Genetics Section, Laboratory of Skin Biology, National Institute of Arthritis and Musculoskeletal and Skin Diseases at the National Institutes of Health. A medical geneticist, Dr. Bale is a member of the NIH team which located the site of the gene for lamellar ichthyosis.

Carl Thornfeldt, M.D., original developer of the new orphan drug Glylorin for the treatment of the ichthyoses, which is presently in phase III clinical trials. He will discuss Glylorin, its properties and development.

Shelly Burdette-Taylor, R.N., who has written extensively on treatment and care issues for the chronic ichthyoses (particularly harlequin ichthyosis).

Heather Halpern, C.S.W., is a specialist in developmental and socialization issues for children with disabilities. She will conduct and moderate our youth group and women's group sessions.

Terri Adams, J.D., is an attorney who specializes in disability rights, patient advocacy, and the law pertaining to patients and families with disabilities. She will conduct a special workshop in disability law as it pertains to employment, education, and public facilities.

THE 1995 F.I.R.S.T. NATIONAL CONFERENCE

When	June 16th, 17th & 18th, 1995 (Fri, Sat & Sun)
Where	The Bahia Hotel & Resort 998 West Mission Bay Drive San Diego, CA 92109
Call	**619-488-0551**
Room	$68.00 per night (family rate)

Family rate means two adults and all children under 18 stay for the flat $68.00 per night rate. For more than two adults (18 and over) in a room, add $15.00 per person.

This rate is guaranteed for 3 nights prior to, and 3 nights following the scheduled conference dates., for a total of 9 nights (June 13th-June 21st). Note that this special rate on the extended days is on a *space available basis*, so be sure to book your rooms well in advance.

The F.I.R.S.T. National Conference rate of $68.00 is only guaranteed for rooms booked a minimum of one month in advance of the conference date — by May 15th, 1995.

You may book rooms at any time by calling the Bahia Hotel at 619-488-0551.

If you have questions, or if you experience difficulties booking your room, please call F.I.R.S.T. executive director Nick Gattuccio in Raleigh, at 800-545-3286.

AIRFARES VIA TRAVEL AGENTS INTERNATIONAL
800-727-6338
919-846-8221
Contact Agent: Linda Puckett

The Travel Agents International office here in Raleigh is the official travel & ticket agent for the F.I.R.S.T. National Conference in San Diego. The agency is offering F.I.R.S.T. the following amenities:

- 5% off already discounted/economy fares;
- All bookings held until final 30 days prior to departure to take advantage of fare drops between booking and departure dates;
- Agency donates 10% of commissions to F.I.R.S.T.

NOTE: Travel Agents International does not guarantee that it can obtain the best possible air fare, so you are encouraged to attempt to obtain more affordable air fares through your own sources.

F.I.R.S.T.

1995 NATIONAL CONFERENCE

June 16, 17, 18 Bahia Hotel

San Diego, California

Cut here and detach

Please Print

Name: ______________________________

Address: ______________________________

City: ____________________ **State:** ________ **Zip:** ____________

Phone: ____________________ **Country:** ____________________

NAMES OF THOSE ATTENDING	adult	child	Age of Each Child	Check here for those affected with ichthyosis
______________________	☐	☐		☐
______________________	☐	☐	________	☐
______________________	☐	☐	________	☐
______________________	☐	☐	________	☐
______________________	☐	☐	________	☐
______________________	☐	☐	________	☐

Type of ichthyosis, if known: ____________________

Your Registration fees will include five meal functions — two continental breakfasts, one luncheon, one dinner banquet, and the opening night reception. Children's fees include all child care costs.

Number of Adults: ________ x $75 = ________
(18 & older)

Number of Children: ________ x $35 = ________
(4 through 17)

Infants & Toddlers: ________ x $20 = ________
(0 through 3)

TOTAL = ________

Cut here and detach

Please Return Registration Fees
With Your Completed Form

Make Check Payable to
F.I.R.S.T.
In U.S. Dollars, Please

Cancellations Will Be Honored
With Full Refunds

UNTIL
The Advance Registration
Deadline:

June 5, 1995

☐ I will need child care for _________ children

NAME	AGE
____________	______
____________	______
____________	______

☐ I am a teen and I'd like to help take care of the children for an hour or two

NAME	AGE
____________	______
____________	______

☐ I am an adult willing to help at the conference for an hour or two (child care, reception table, etc).

NAME

____

____

☐ I am a teen or young adult and I'd like to participate in a discussion group with others my age.

NAME	AGE
____________	______
____________	______

PLEASE MARK THE APPROPRIATE BOXES

☐ This is the first National Conference I have ever attended

☐ I have attended National Conferences in the past (City/year): ____________

____

____

☐ I will be staying at the Bahia Hotel in San Diego

☐ We are combining the National Conference with a family vacation

We're traveling the following number of miles to attend this Conference (mark the appropriate box)

☐ 0 - 150 ☐ 150 - 500 ☐ 500-1000 ☐ 1000 - 1500 ☐ 1500 - 2500 ☐ over 2500

For hotel information & reservations, call the Bahia Hotel at **619-488-0551.** Identify yourself as a F.I.R.S.T. member to receive our special conference hotel rate of $68.00 per night. This rate is good from 3 days prior to the Conference to 3 days following — from June 13th through June 21st.

Your reservation must be made by May 15th, 1995

Questions about the conference or trouble booking a room? Call Nick at F.I.R.S.T. at 800-545-3286

Please Complete and Return This Form to F.I.R.S.T. With Your Payment In Full
In U.S. Funds Please.

Mail to: F.I.R.S.T. / P.O. Box 20921 / Raleigh, NC 27619-0921

1995 NATIONAL FAMILY CONFERENCE SCHEDULE

Following is the advance schedule for the National Family Conference in San Diego, June 16, 17 & 18. The schedule is subject to change at this point, although it is not expected to change significantly. See articles on pages 1 and 6 for more details about the conference offerings.

Friday, June 16th

Registration
3:00 - 7:30 pm

(also open Saturday morning at 8:30 am)

Registration desk will open at 3:00 pm and will remain open until Friday evening Reception events begin, at about 7:30.

This is a simple matter where members simply check in and pick up their Conference registration packets.

Opening Night Reception
7:00 - 10:00 pm

A casual opening night reception for all attendees. Hors d'ouvres and light snacks will be served and a cash bar will be available.

The evenings program will consist of welcoming comments, introductions of your board of directors, the Conference faculty, and other special guests, and some introductory and orientation about the Conference program.

The main focus will be meeting one another, socializing, breaking the ice, and just having fun.

Saturday, June 17th

Breakfast
8:30 - 9:15

Opening Remarks

General Session #1
9:30 - 10:15

BREAK

BREAKOUT SESSIONS #1
10:30 - 12:00

Session 1-A	Session 1-B	Session 1-C	Session 1-D

HOSTED LUNCH
&
FAMILY BREAK PERIOD
12:00 - 2:00

General Session #2
2:00 - 2:40

BREAK

BREAKOUT SESSIONS #2
3:00 - 4:30

Session 2-A	Session 2-B	Session 2-C	Session 2-D

BANQUET at 6:30 pm

Sunday, June 18th

Breakfast
8:30 - 9:15

General Session #3
9:15 - 10:00

BREAK

BREAKOUT SESSIONS #3
10:30 - 12:00

Session 3-A	Session 3-B	Session 3-C	Session 3-D

LUNCH
ON YOUR OWN
12:00 - 1:30

PANNEL DISCUSSION/
QUESTIONS & ANSWERS
1:30 - 2:45

CONFERENCE CLOSING
2:45 - 3:00

8:00 am
9:00
10:00
11:00
Noon
1:00 pm
2:00
3:00
4:00
5:00

Regional Support Network (RSN)

RSN NATIONAL OFFICE
PROGRAM DIRECTOR
Heather Gattuccio
4279 The Oaks Drive
Raleigh, NC 27606
919-859-2712

REGION ONE
NY, PA, VT, NH, NJ, CT, RI, MA, ME
Shelly Licursi
311 White Birch Drive
Cinnaminson, NJ 08077
609-786-8766

REGION TWO
DE, MD, WV, VA, NC, SC
Robin Joyce
Route 1, Box 189-F
Sandy Ridge, NC 27046
(910) 871-3277

REGION THREE
TN, GA, FL, AL, MS, LA, AR
Debra Bowie
3694 Shady Hollow Lane
Memphis, TN 38116
901-346-0513

REGION FOUR
KY, OH, IN, IL, MO, MI
Cynnie Bates
133 Elam Park
Lexington, KY 40503
(606) 276-0142

REGION FIVE
WI, MN, IA, ND, SD, NE
Carolyn Gramlich
535 West Sandhurst, #111
Roseville, MN 55113
612-483-7700

REGION SIX
TX, OK, NM, CO, KS
Donna Rice
2902 West Elm Circle
Katy, TX 77493
(713) 391-4407

REGION SEVEN
WA, OR, ID, MT, WY, AK
Sheri Gelivich
1344 S.E. Rex
Portland, OR 97202
(503) 236-3203

REGION EIGHT
CA, NV, UT, AZ, HI
Chris Beeler
1002 E. Gifford Drive
Tucson, AZ 85719
(602) 887-7188

Netherton's Syndrome Contact
Cathy Sipper
Rt. 1, Box 300
Laverne, AL 36049
(205) 334-6827

Canadian Contact
Barbara Rockwell
3080 Ballydown Crescent
Mississauga, Ontario L5C 2C8
(416) 896-9620

STATE CONTACTS

Indiana
Mark & Jill Wood
317-841-9923

Kansas
Tiffany Karst
913-268-3692

Mississippi
J. Charlene Wiggins
601-769-2454

New York
Cathy Lopez
718-842-7269

South Carolina
Nancy Bryant
803-881-2036

Wisconsin
Theresa Tremmel
414-538-4922

Anyone wishing to become a state contact person should call the RSN National Coordinator, Heather Gattuccio, to obtain an application.

In Memorium

We are enormously grateful to these, who have made gifts to F.I.R.S.T. in rememberence of friends and family recently departed

In Memory of	***From***
Mrs. Selena D'Avanza	Joe & Chris LaBarbara
Mrs. Tommye Jelinek	Joe & Chris LaBarbara
Mrs. Pam Gillihan	Joe & Chris LaBarbara
Michael & Mary Amato	Chris & John Aanderud

This is a donation in honor of our son, who died on February 3rd. He was a collodion baby, our second (the first one is healthy and 3 years old), and he died from complication from the ichthyosis. His name is Nathanel. We are very sad.

Anne & Arieh Breslow
Efrat, Israel

SPANISH TRANSLATION OF F.I.R.S.T.'S *MANUAL FOR TEACHERS* DUE OUT SOON

Special thanks go to Simon Tarlovsky, a F.I.R.S.T. member living near Mexico City, Mexico, who has taken it upon himself to translate into Spanish some of F.I.R.S.T.'s patient education material.

A special priority, we have sought aggressively for some time to obtain Spanish translations of our material. Mr. Tarlovsky (who will be attending the conference in San Diego) delivered a full translation of our book, *Ichthyosis: A Teacher's Manual*, to the office last month. The manuscript is presently being reviewed by native Spanish speaking physician at Duke University Medical Center, and will then be typeset at the office and made available soon after we return from San Diego, in late July.

Anyone interested in obtaining Spanish language material should contact Nick at the office in Raleigh.

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.

"PERSONAL RESPONSIBILITY ACT"

The House Welfare Reform Bill Will Hurt Children & Families With Disabilities

Part of the Republican-led budget-cutting fever that is sweeping Washington is on the verge of creating some crippling unintended side effects from legislation recently passed during the House's 100-day assault on the now famous Contract with America.

- Disabled children who currently receive Supplemental Security Income (SSI) because of an Individual Functional Assessment (IFA) would lose all benefits (both cash and Medicaid) if the IFA provision is repealed under the Personal Responsibility Act — the House Welfare Reform bill. This proposal has been passed by the House of Representative.
- If the bill passes the Senate, approximately 225,000 disabled children will lose all SSI benefits and Medicaid, and 600,000 will lose cash SSI benefits. In the future, millions more will be denied SSI and Medicaid because the Social Security Administration (SSA) will be unfamiliar with rare diagnoses.
- The Personal Responsibility Act makes the assumption that children who qualify for SSI under an IFA are not as severely disabled as those who meet one of the SSA's "official" impairment listing. Ichthyosis is NOT on the SSA's official "Listing of Impairments." In fact, most rare disorders are not on the Social Security Administration's "Listing of Impairments."
- Under the Personal Responsibility Act, Medicaid and SSI would only be available to children who meet the medical listings AND are institutionalized. This not only means many children could lose their SSI benefits and Medicaid, but that some people with rare disorders might be inappropriately institutionalized by parents who cannot afford the high medical costs associated with keeping disabled children at home.
- In addition, this bill would end many federal-state assistance programs that benefit those with disabilities, including Aid to Families with Dependent Children (AFDC), Emergency Assistance (AE), child care, child welfare, nutrition assistance, and it cuts funding for food stamps. Disabled adults who cannot work will also suffer immeasurably because of this law.
- By replacing many of these programs with block grants to states, you and your state may end up receiving significantly less federal funding for disabled children's programs.

There is still a chance to have these provisions defeated by the Senate, but his will happen only if people with disabilities — especially those with rare, "orphan" diseases — speak out to their Senators and Congressmen.

Write or call as many U.S.Senators as possible! Tell them you support the Individual Functional Assessment (IFA) in the SSI program, and tell them that rare disorders are not on SSA's Listing of Impairments. Therefore, the Personal Responsibility Act would disqualify children with many serious rare disorders from SSI and Medicaid.

Ask your Senators to VOTE AGAINST the House Welfare Reform Bill, commonly known as the "Personal Responsibility Act."

YES!

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

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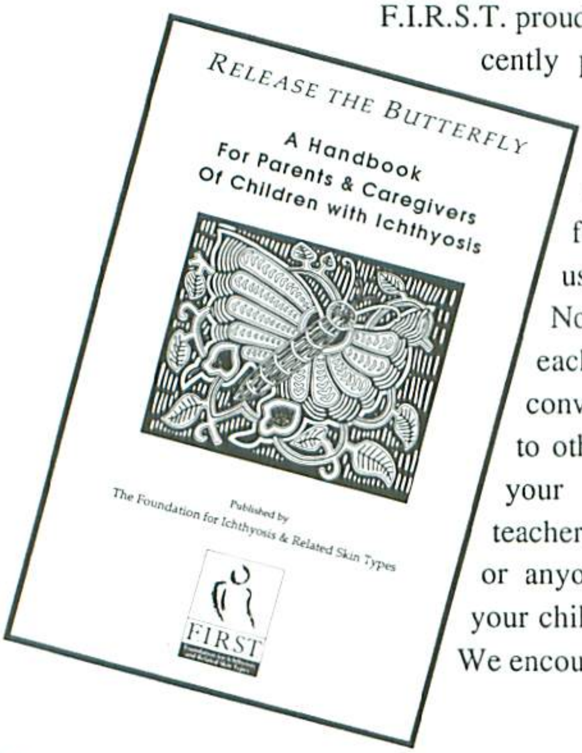
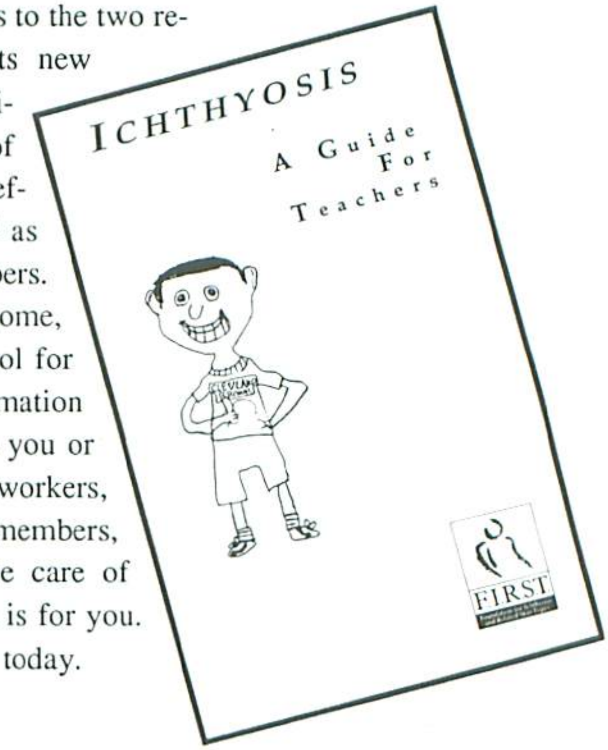


F.I.R.S.T. proudly introduces members to the two recently published books in its new Patient Education Library. The outcome of nearly three years of effort , both are intended as useful tools for members. Not only useful in the home, each can be a valuable tool for conveying important information to others who interact with you or your child—child care workers, teachers, employers, family members, or anyone else for whom the care of your child is as important as it is for you. We encourage you to order both today.



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