

Ichthyosis Focus



Vol. 26, No. 1

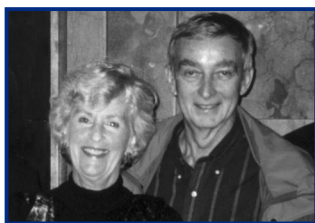
A Quarterly Journal for Friends of F.I.R.S.T.

Spring 2007

Ichthyosis and F.I.R.S.T.: An Historical Perspective

By Janet Weary

The following is an address presented by Janet Weary at the 1993 8th National Family Conference in Chicago, Illinois.



Dr. Peyton and Mrs. Janet Weary

I want you to know that I feel great admiration for all of you. I am no longer parenting a child with ichthyosis, for she has, by any standards, achieved a large measure of contentment and success.

And I never personally had to cope with the physical discomforts that many of you have every day of your lives. It never occurred to me to create a national foundation, which you have done. I stand in awe of your accomplishments in a world that is often not supportive. Your knowledge is much greater than ours was in the fifties, sixties, and seventies, and, of course, many of you are actively involved in sophisticated research in the field of skin disorders. But I know where you are coming from, because, of the four children that Peyton and I had, two were born with Epidermolytic Hyperkeratosis; our first a daughter, who is now an adult, and our last, our son, who survived for only three days.

When our daughter Terry was born in 1954, my obstetrician and pediatrician did not know what was wrong. Our pediatrician finally diagnosed epidermolysis bullosa because of the extensive blistering. But Edward P. Cawley, then chairman of Dermatology at the University of Virginia, called her condition Congenital Ichthyosiform Erythroderma. Neither Peyton nor I had the condition, nor was there any record of it in either family. It was assumed to have been caused by recessive genes in the rare occasion of two parents carrying the gene.

In 1954, genetic mutations were not every day news, as they are today, and it was years later that Terry's condition would be identified by the name Epidermolytic Hyperkeratosis. You would probably not be surprised at the number of doctors, including dermatologists, who continued to disagree or be unconvinced. Dr. Cawley became a pillar of strength for us and I will never forget his kindness and patient counsel, then and throughout Terry's childhood. I would wish for each of you a doctor whom you can trust and the development of a true partnership between you.

When Terry was born, my husband was still a student, and we had to learn many of the things you had to learn, and some you already know. We learned that cortisone cream (the newest miracle drug at the time) wasn't going to work and couldn't have been used continuously anyway. We learned about the need for prompt antibiotic treatment for infected blisters. To this day, Terry often has trouble getting antibiotics when she knows that a strep infection is winning, but her doctor doesn't. We had so many trials and errors, as far as treatment went, that I don't remember them all. I do remember some foolish indulgence in daydreams about magic cures on my part and some flirtations with treatments that were risky, impractical, or uncomfortable. Through them all Terry persevered. We had to learn about her intolerance to heat and very cold, dry temperatures, and how to keep a swim in the ocean from being a misery for her, while being a pleasure for the rest of the family. We had to accept her limitations with physical activities and we had to learn how important it was to teach the people in her life about them, and our concern for her emotional well-being. We weren't always successful. We had some baby sitters who were afraid they would "catch it" and some children whose mothers had the same fear. But, for the most part, intelligent people can handle what they can understand and it is important to make the effort, even when it is not easy, to help them.

At the beginning of each school year, I went to school before classes began and talked with Terry's teachers about her condition and how it might affect her physically and emotionally, according to her age. Without exception I found her teachers to be cooperative, supportive, and very appreciative of the help this was to them. I did this for a number of years, until we felt Terry could handle things herself. But even when she was an adult, her father provided her with a simple letter of explanation, the name of her skin condition, that it was congenital and not contagious, and suggested medications should she need a prescription from a strange doctor. She carried it with her to Switzerland one summer when she was 17 and had it at college if needed.

I am not going to tell you that life was easy; you know it wasn't. We tried to teach our daughter that those who discriminated against her needed to build themselves up because of their own insecurities. This was not an easy lesson for a little child to understand, but she tried. Our generation was not brought up to be very open to others

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Ichthyosis Focus is published quarterly by the Foundation for Ichthyosis & Related Skin Types

Requests to reprint information contained in Ichthyosis Focus should be directed to the editor.

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The Foundation for Ichthyosis & Related Skin Types is a 501 (c) 3 charitable organization supported by public and private donations. All contributions to the Foundation are tax deductible to the full extent of the law.

The editor invites your correspondence. We welcome your comments, observations and suggestions. Please send your letters to Ichthyosis Focus at the address listed above.

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F.I.R.S.T. Volunteers Excel at Grassroots Fundraising

Grassroots fundraising is an important part of the Foundation's financial success. Volunteers who make the effort to host fundraising and awareness events in their communities are one of our most important resources. Here is what a few of our friends accomplished in recent months.

Monster Dash

Dawn Johnson and her family hosted a Monster Dash fun run and walk on October 28, 2006, in Friendswood, Texas. (Dawn's daughter is affected with EHK.) This annual event brings together family, friends, and the local community for a fun-filled morning of exercise, costumes, raffle prizes, and refreshments. The Monster Dash is always successful in raising funds for the Foundation and promoting awareness of ichthyosis in the community. If you are interested in copying the Monster Dash format and hosting an event in your community, please contact the Foundation office at 1-800-545-3286.

Creative Memories Scrapbooking

Sarah Hodgkinson of Ontario, Canada, decided to take a hobby that she loved, scrapbooking, and use it to raise awareness of ichthyosis and to benefit the hospital that had done so much for her daughter, who is affected with CIE. Partnering with Canadian Scrapbook and Scrapbook & Cards Today, Children's Charity Crop was launched. Weekend-long scrapbooking classes and events will be held in six major cities across Canada. Proceeds from these events will benefit the Children's Health Foundation and local children's hospitals. For more information about these events, go to www.csc4k.com. To see a profile of Sarah and the beautiful winter scrapbook page she created for her daughter, go to www.scrapbookandcards.com, Magazine/Winter issue '06, Pages 20 to 22.

Caravan Beads

Kimberly Mayone of South Portland, Maine, hosted a fundraiser with Caravan Beads on October 2, 2006. Beads, bracelets, awareness of ichthyosis, and fun were the focus of the evening. Thirty percent of sales went to F.I.R.S.T.

A notice on the editorial page of the Mayone's local newspaper advertised the event and provided information about ichthyosis and F.I.R.S.T. Kimberly's son is affected with EHK.

Local Women's Club Support

Eustolia Perez, of Edinburg, Texas, partners regularly with her local women's group, the Zonta Club of West Hidalgo County, to direct funds to F.I.R.S.T. Eustolia is affected with lamellar ichthyosis.



Eustolia Perez with Zonta Club President, Deitrah Davis

Bank Staff Contribute Through Jeans Day

Team members of the Granite Run office of Sovereign Bank, Lancaster, Pennsylvania, contributed proceeds from their quarterly Jeans Day to F.I.R.S.T. in honor of Janet McCoy's daughter who is affected with CIE.

Sweet Success

Shelly Trojanowski, of Hillside, Illinois, hosted a community bake sale in honor of her son who is affected with CIE. The event was coordinated with Ichthyosis Awareness Week and proceeds were directed to ichthyosis research.



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Ichthyosis and F.I.R.S.T.: An Historical Perspective

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about our feelings, especially to our children (talk shows and self-help books were totally unknown to us) and we muddled through with our copies of *Dr. Spock* as best we could. I knew absolutely no one who shared my problem. My support system was our wonderful parents, especially my mother who was never too busy to give me a break. They and our close friends treated all our children with loving acceptance and my husband always made me feel that he would take care of us. It wasn't easy for our other daughters; I wish they had a kind of Ichthy-Anon, like Al-Anon, for siblings because we were not able to share and discuss our feelings as much as we know we should have. It was particularly difficult for them when our son died. If there is one thing I wish I could do over, it would be to have been more aware of their pain in the midst of my own. But now I see in these daughters the kind of compassion and empathy for others that seems rare among people, and that they will in turn pass this rare quality on to their children. I see also that there is more open communication between parents and children, more freedom to express thoughts and feelings on the part of both generations.

I think it is not surprising that as Terry grew up she became interested in the medical fields. When she worked as a volunteer candy-striper at our local hospital, she became aware of the vast numbers of people who have physical imperfections, ranging from acute and temporary to the permanently disabling. Eventually she worked as a nurse's aid and physician's assistant. There were always many friends, and she has remained in contact with the closest of them from high school and college.

Terry now holds a PhD in molecular genetics and is the CEO of the biotech company Mitotyping Technologies, LLC. She is married to a fine man and they have two children whom they adopted. The decision to adopt came after long and careful consideration of all aspects of their beliefs, feelings, and plans for their future. It is not a recommendation to others; it was simply the answer for them.

It is interesting that Terry works in the field of DNA technology, a field that has given us new knowledge about epidermolytic hyperkeratosis. I'm sure that even if she never contributes directly to a "big cure," her involvement in this field brings her great satisfaction.

I asked our daughters what they would like to say to you. Our youngest said, "Tell them that siblings with normal skin, because they were born physically 'perfect,' can feel that they have no excuses and need to be perfect. When they are not, they can feel they have somehow failed. So-called perfection can also be a burden."

Our middle daughter said, "If there is one thing I would change about how we deal with ichthyosis as a family, it would be to increase the openness among us, because when ichthyosis is unspoken it can become omnipresent. Questions can become worries and answers sought without counsel can suggest to the sister or brother that he or she is somehow responsible." And this, "It is much easier, I think, to be grown up than to grow up. Maturity brings strength and the ability to shape things from the stuff you are given."

And, finally, Terry said, "Tell them how important it is for a person with ichthyosis not to feel identified only by his or her skin, but by the recognition of some positive thing; be it a special talent, ability, accomplishment, experience, service to others, adventure, achievement, etc. Look for your special thing in life, whatever it may be. This means of course that you must work for it just as everyone else does. And it also means that those of you who are parents, siblings, and friends must be supportive while also giving your child, sibling, or friend the space to find his or her own independent life."

Dr. and Mrs. Weary were honored for their many contributions to the Foundation at a testimonial dinner held in Washington, D.C. on February 1, 2007. See page 4 for more details.

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2007 Testimonial Dinner

Honoring Drs. Gloria & James Graham and Dr. Peyton & Janet Weary



Drs. James and Gloria Graham

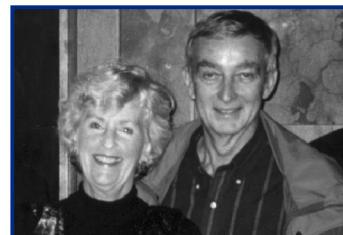
On February 1, the "Who's Who" in dermatology gathered at the exclusive Cosmos Club in Washington, D.C. to pay tribute to Drs. Gloria and James Graham and Dr. Peyton and Mrs. Janet Weary at the Foundation's 2007 Testimonial Dinner. As one guest commented, "I have never been in a room filled with such notable dermatologists in my entire life. The amount of clout present at this function is amazing and speaks volumes about the careers of our honorees."

The Grahams and Wearys are truly deserving of this incredible honor. As practicing dermatologists for more than 50 years, Jim and Gloria Graham and Peyton Weary certainly have made a lasting impression in their field.

Jim and Gloria Graham were pioneers in the field of cryosurgery and have taught and mentored future generations of dermatologists. Peyton Weary is a past president of the American Academy of Dermatology and was instrumental in developing the Coalition of Skin Diseases. Both Gloria and Peyton have served on the Board of Directors of the Foundation for Ichthyosis for many years and have helped to guide the mission and growth of the Foundation. Janet Weary has been an instrumental figure in F.I.R.S.T., serving on the board of directors in the earlier years of the foundation. She spent countless hours being a voice, mentor and friend to many families.

Dr. Boni Elewski and Dr. Kenneth Greer served as co-chairpersons for the event as friends, family members, and professional colleagues gathered to pay tribute to the Grahams and Wearys untiring efforts for patients affected with ichthyosis. The highlights of the evening included the tributes given by the honorees' children, Reverend Wayne Graham, who spoke about his mother, Gloria, and Terry Melton, who spoke about her parents, Janet and Peyton.

The event raised more than \$30,000 for the Foundation's general operating budget. The Board of Directors and the Foundation staff are extremely grateful to the Grahams and Wearys for having allowed the Foundation to host this successful event in their honor.



Dr. Peyton and Mrs. Janet Weary

**Warmest
Congratulations to
Drs. Gloria & Jim
Graham
and Dr. Peyton &
Janet Weary
From All of Us at**

THE
NEOSTRATA
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**Congratulations to
the Grahams &
Wearys
Your dedication to
dermatology and
patients with
ichthyosis is
inspiring.**



Executive Director's Report

Dear Members & Friends of the Foundation,



Each year, at the annual American Academy of Dermatology convention, I have the privilege to meet with the Foundation's Medical and Scientific Advisory Board (MSAB). This board is comprised of the world's leading experts on ichthyosis and related skin types. This year's meeting was held in Washington, DC, from February 3-6, and the traditional format of our annual breakfast meeting featured a new twist. The first segment of the meeting focused on the present and future business of the Foundation. I was very proud to share the exciting highlights from the past year (conference, research program, fundraising successes, etc.) and just as proud to announce our future projects, including a new four-year strategic plan and more research funding.

For the second segment, we introduced a new concept which was a huge success. Each member of the MSAB was invited to bring a difficult ichthyosis case to discuss among their peers. Six cases were presented. It was truly an amazing experience to watch these physicians share their years of experience and insight with each other. The care and concern for these patients was truly inspiring.



F.I.R.S.T. MSAB Members view a patient case and discuss best treatment.

The MSAB greets two new members to join the already elite group of dedicated professionals. The Foundation welcomes Dr. Matthias Schmuth, a dermatologist from the University of California at San Francisco, and Dr. Brandon Newell, a pediatric dermatologist at Children's Mercy Hospital in Kansas City, Missouri. Drs. Joseph McGuire and Virginia Sybert rotated off the MSAB this year, but promise to remain involved on our Physician Referral List.

Dave Scholl, the Foundation's president, and his wife, Valerie, voluntarily joined me in Washington, DC for the weekend. We shared many exciting ideas for the future growth of the Foundation. We visited and thanked our pharmaceutical partners and met with many people who share a genuine interest in serving the ichthyosis community. Dave and Valerie took an active role in helping the Coalition of Skin Diseases by helping to build the exhibit booth in the convention hall. It was an all day affair and I was very appreciative of their involvement.

During my trip to Washington, DC, I was accompanied, for the last time, by Maureen Tierney, our outgoing Program Director. At the MSAB meeting, I was extremely pleased to present her with a gorgeous engraved pewter serving tray. The tray was a symbol of our thanks as she transitions into her new career in the culinary arts industry. I will miss Mo greatly but also welcome her successor, Moureen Wenik, who will continue to advance the incredible paths Mo has paved for the ichthyosis community.

Moureen Wenik, who also goes by the nickname "Mo" joins our staff with over 17 years of non-profit experience in a local YMCA program. I am confident that her warm personality, eagerness to help our members, and hard-working attitude will make her a great addition to our team. Please join me in welcoming her to the Foundation.



The Foundation welcomed three new members who joined our Board of Directors in January:

- Cort DeHart is the father of an affected daughter and an attorney from Fort Worth, TX. Cort also founded Project SOS, a non-profit organization whose mission is to raise money for lamellar ichthyosis research;
- Jonathan Dyer, MD is a pediatric dermatologist from Columbia, MO, who attended our past two family conferences and has a very special interest in treating patients affected with ichthyosis; and,
- Angela Godby is an affected adult from Alexandria, VA, and current chair of the Foundation's Advocacy Committee. Angela will bring her years of experience from working on Capitol Hill and other governmental agencies to the Foundation.

2008 Family Conference

The date and location for our next conference has been selected as Chicago, Illinois at the end of June. The official dates will be confirmed shortly. Visit our website, www.scalyskin.org in the near future for more details.

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Executive Director's Report

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After nine consecutive years of service, Mary Williams, MD, has rotated off our Board of Directors. Mary is one of our Foundation's co-founders and has been instrumental for the past 25 years in helping the Foundation grow and prosper. Although Mary will no longer serve on our Board, she has been elected as the Foundation's first-ever Board Member Emeritus.

Sincerely,



Jean R. Pickford
Executive Director

Board of Directors



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Grandfather of affected child, CIE
President & CEO,
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Athens, Ohio



Michael Briggs
Grandfather of affected child, EHK
Retired Vice President,
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Vice President
Professor, Division of Dermatology
University of Washington
Principal Investigator,
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Lamellar Ichthyosis
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Columbia, Missouri



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Father of affected children,
Lamellar Ichthyosis
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Peyton Weary, MD
Father of affected children, EHK
Former President, American Academy
of Dermatology
Professor of Dermatology, University of
Virginia
Charlottesville, Virginia

Annual Report *Fiscal Year 2006*

President's Report



Greetings to all Members and Friends of F.I.R.S.T.:

Soaring to New Heights was our theme for the Foundations' 2006 Family Conference in Atlanta, GA, and I believe this metaphor aptly describes both our past operating year and our focus on long-term, strategic goals that will sustain the growth required to meet our critical mission of service to those affected with ichthyosis and related skin types.

This special, 25th anniversary theme was carefully chosen. Throughout the year, we hoped to bring attention to the rich history of our organization, recognition and respect to founders, members, and directors instrumental in establishing and nurturing F.I.R.S.T. to "graduate" status; and a motif of celebration and exuberance befitting the unique energy, passion, dedication, and love of all those affiliated with our organization.

Beautiful, multicolor hot air balloons rising in the sky appeared on each shirt commemorating the Conference. This same visual inspires when I reflect on several projects that sustained momentum and a few exciting, unique projects that *took flight* in 2006 or are *set for take-off* in the future!

Chief among the major accomplishments this past year was the awarding of F.I.R.S.T. - sponsored research grants to four outstanding clinical and basic scientists in the U.S., France, and Israel. The risks associated with designing and implementing a research program for F.I.R.S.T. are high, but the potential rewards to our members are simply too great not to apply our strategic focus in this direction.

Launching these grants in 2006 is a fantastic example of our strong roots as an organization. From early strategic thought, to gathering input and support from our members for this lofty initiative, to raising substantial funding to financially support the Research Program, to identifying knowledgeable scientific advisors that could develop and guide the program goals, objectives and policies, to the focus on successful execution by our wonderful and talented staff led by Executive Director Jean Pickford and the expert direction by research program manager Maureen Tierney, in the truest sense of a "*we can do it*" volunteer spirit as an organization, we did it!

Many, many volunteers deserve recognition for sustaining the momentum *on the ground* while assembling "the balloon" over the five year path to launch. Combined with the financial commitment and generosity of so many that supplied the *hot*

air to make the balloon rise, your collective efforts were rewarded and we had *take-off* in 2006.

We invite you to stay tuned for periodic updates in the newsletter on the scientific progress these important projects make in better understanding EHK, lamellar, and other Ichthyosis-related skin diseases. Furthermore, our 2007 Request for Proposals (RFP) was published to the scientific community in January. This RFP resulted in another set of grant applications from which the Board expects to identify those of the highest quality and impact and extend financial support to at least three of them. The announcement of 2007 awards is expected to take place during the summer and will be announced in the newsletter as well.

Speaking of the newsletter and why it is such an important communication tool for F.I.R.S.T., and the impact it can have on readers, I wish to share with you the following truly inspirational story.

Phone calls to F.I.R.S.T. are not unusual at all. Most often, they are from people in need of help or assistance or express a need for services, educational information, a physician referral, or simply someone to talk to. Our staff is always looking to help our members.

During this past year, however, our executive director received a somewhat different phone call. It was from the nephew of a woman who had been an avid reader of our newsletter for many years. In later years, her eyesight declined but she would insist that her nephew read her the F.I.R.S.T. newsletter from cover to cover, thus allowing her to stay abreast of the Foundation's activities and progress.

The primary reason for the nephew's call was to let F.I.R.S.T. know that his aunt had bequeathed a generous donation to our organization. He said that she had always enjoyed reading about the various sponsored activities of the organization, new educational materials about Ichthyosis, and news from the family conferences.

In my view, this donation was her way of personally, and directly saying, "*Keep it up, you are making a difference*". Demonstrating service to others, this time in the form of a generous donation, enables us all to *Soar to New Heights!*

Recognizing that some members experience a difficult financial decision and undue hardship when it comes to attending family conferences, the Board of Directors has

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Annual Report *Fiscal Year 2006*

President's Report

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charged an *ad hoc* committee with the responsibility of developing a Family Conference Scholarship Program, whereby a portion of these funds can be used by families and individuals in great need so that attending a family conference is within reach, in honor of Jean Giroux.

How exciting! From a newsletter and Jean's generosity, more individuals and families may be able to benefit from attending the 2008 Family Conference in Chicago, IL, where they can learn more about Ichthyosis, have a professional screening, network with other members, and enjoy the celebration dinner and dancing that is always so memorable at our family conferences. Thank you Jean!

In closing, and as the directors of our organization embark in June on strategic planning that will establish new goals for the next four years, I openly ask for your direct input either by e-mail, phone call, or letter. Among the many topics that will be discussed, we seek your thoughts on how well our core support and educational programs are working for you; how valuable and useful you find the scheduled activities and educational sessions at the family conferences; do you have a way of making our Research Program even better, or new fundraising ideas to help it soar; and, do you have a view of how the application of new technology can bring patients, families and

physicians, and professional services closer together? Please, let us know.

On behalf of the board of directors and professional staff, thank you for your continued support of F.I.R.S.T. Have a great year in 2007. We look forward to seeing you in Chicago in the summer of 2008.

Sincerely,



David R. Scholl, Ph.D.
President



Chief Financial Officer's Report



Dear Members and Friends:

As you can see from our audited financial statements, 2006 was a breakthrough year for the Foundation. Another unqualified opinion from our auditors, McGladrey & Pullen, LLP, was expected, but our most noteworthy achievement was the overall improvement in our financial condition

and ability to reach out to others. As anticipated, the increased focus on research funding and related programs kept everyone quite busy. A substantial amount of time was spent reviewing

current and long term donor commitments and to what extent we could make our own commitments to fund programs. I can assure everyone, your Board taxed themselves in making sure the Foundation reached out to as many as possible while maintaining a solid financial reserve to protect its ability to operate responsibly.

The Statements of Financial Position included in this issue of Focus, our Net Assets increased by \$174,723 or 92 percent over last year. Total equity increased by 35.2 percent and unrestricted equity increased by 24.5 percent illustrating our continued improvement in financial strength. On another

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Annual Report *Fiscal Year 2006*

Chief Financial Officer's Report

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positive note, our unrestricted equity can provide for 1.5 times our annual operating expenses (not including research funding) based on our 2007 expense budget, a key strength factor especially in the not for profit world.

On the revenue side, we had an increase of 140 percent in contributions, primarily due to receiving \$360,000 more for Donor Designated Research in 2006 compared to 2005. Just

looking at revenue excluding Donor Designated Research, revenues still increased \$84,000 or 26 percent. Almost \$22,000 of this came through direct solicitations from your Board of Directors. This is a phenomenal increase and, hopefully, a sign of things to come. From an expense standpoint, expenses were in line with budget. Management and General Expenses increased by only \$11,000, which was very close to budget and related mostly to expected increases.

So what does the future hold? Hopefully more of the same.

As a conservative financial person, I do not want to look too close into my crystal ball, but experience tells me the Foundation has started on a new, exciting path that will result in more benefits for more people in need. As hoped and planned, we have developed the ability to fund significant research. Not resting on its past success, however, the Board continues to look for new ways to increase fundraising efforts. Remember though, you, too, can help. Please let Jean know if you have an idea that might be worth pursuing or have a person worth soliciting. Just send a note to the office or e-mail her directly.

Sincerely,



John J. Schoendorf
CFO, Board of Directors

**The Statement of Financial Position is excerpted from the Foundation's audited financial statements as of September 30, 2006. A complete copy of the audited financial statements and the independent auditor's report are available and can be obtained by calling the national office at 215-619-0670 or 1-800-545-3286.*

Foundation for Ichthyosis and Related Skin Types, Inc.

Statements of Financial Position September 30, 2006 and 2005

	2006	2005
Assets		
Current Assets		
Cash	\$ 420,972	\$ 250,407
Marketable securities	244,883	225,746
Pledges receivable	150,000	10,317
Prepaid expenses	4,350	1,952
Total current assets	820,205	488,422
Cash, permanently restricted	10,000	10,000
Furniture and Equipment, net	2,891	2,195
Total assets	\$ 833,096	\$ 500,617
Liabilities and Net Assets		
Current Liabilities		
Grants payable	\$ 150,000	\$ -
Accounts payable and accrued expenses	11,407	3,651
Total current liabilities	161,407	3,651
Net Assets		
Unrestricted	439,142	352,596
Temporarily restricted	222,547	134,370
Permanently restricted	10,000	10,000
	671,689	496,966
Total liabilities and net assets	\$ 833,096	\$ 500,617

See Notes to Financial Statements.

2006 Contributors List

\$10,000 +

Allergan
Michael & Lynn Briggs
Josh & Amie Jo DeGarmo
Dawn Johnson - Grass Roots Monster Dash
Arnold Kovin
NeoStrata Company

\$5000 - \$9999

Barrier Therapeutics, Inc.
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F.I.R.S.T. Volunteers Excel

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Garage Sale Match

Edie Wohlgang, of Mayfield Village, Ohio, hosted a garage sale fundraiser and then convinced her local Wal-Mart to match the money she raised. The Wal-Mart Foundation supplied the matched funds.

Edie's grandson is affected with EHK.

Honoring a Loved One

Julie Pratt, of Brattleboro, Vermont, and her family reached past their grief at the loss of Julie's grandmother, Mildred Feinberg, and asked that donations to F.I.R.S.T. be made in lieu of flowers.

The Pratt family directed that donations go to EHK research because Julie's daughter is affected with EHK.

The Foundation is so thankful to these members and to everyone who raises funds for the foundation and, most importantly, helps to educate the community about ichthyosis and what it means to live with these conditions.

Thinking of hosting a Golf Tournament to benefit F.I.R.S.T.? **The Golf Tournament How to Guide** is available to assist you in making this happen. The guide gives you the tools to organize the most successful tournament. The guide addresses promotion, site selection, prize donations, and tournament formats. Please contact the office for your copy of sample of letters, registration forms, and brochures.

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Spotlight On...

Diana Gilbert
Living with Ichthyosis: My Skin Story



Diana with husband James and daughter D'Jae

My name is Diana Gilbert and I am 31 years old. I have Ichthyosis.

When I was born in 1975, doctors in Bermuda were unsure of the skin condition that I had and suggested my parents send me to the Great Ormond Street Hospital in London,

England. There, they had diagnosed me with ichthyosis. Ichthyosis is best described as a family of genetic skin diseases characterized by dry, thickened, scaling skin. It is **not** contagious. There are many types of Ichthyosis, such as Lamellar Ichthyosis (LI), CHILD Syndrome, Epidermolytic Hyperkeratosis (EHK), and Congenital Ichthyosiform Erythroderma (CIE). Problems like overheating, tightness of the skin, impaired hearing or sight are associated with ichthyosis.

The type that I have is Netherton Syndrome (NS), which means that the skin is generally red, can be scaly, and may itch. My hair is fragile, short, and bamboo-like. NS usually is noticed at birth. And normally we are very tiny in size as babies and children. But it does change, as we get older. Infections are also common with NS sufferers. Netherton Syndrome is transmitted when both parents carry the same gene that will pass NS on to their children. There is a 25 percent chance it will be carried over to the children, which is why I have it, but it has skipped my 14-year-old brother, Brian.

Growing up was difficult for my family and me. As with any family with challenges, we had to learn to cope with my skin condition. School was always a problem for me, as I faced teasing and was bullied all the time. Through it all, my parents are there to guide me through any hard times that arise because of my skin. We have shared many tears and laughs. Thanks, Mom and Dad!!

Once I began Bermuda College, things finally started to change. I began to make friends. Many people seemed to make their own assumptions about my skin; however, I felt that knowledge was what they needed. Here I was able to have a voice, to speak out and inform them of my condition.

After college, I started another step in my life, working. Once again, knowledge played a key role in this environment, and I felt very privileged to have a very accepting department at

Butterfield Bank. I am grateful that they gave me the chance to prove myself academically, while learning more about my skin. Special thanks to my manager, Cynthia Dias, and the rest of the LOC team.

At the age of 22, I achieved another goal, which, growing up as I did, never felt attainable. I got married!! James and I have been married for 9 years, and he has truly been my motivation when it comes to dealing with my condition. On a few occasions, when my skin had gotten really bad, he was there through it all. He is very supportive and always offers great suggestions on improving the way I may look and feel.

In 2003, another great step in my life occurred. I became pregnant and had a baby girl!! D'Jae has truly been my greatest blessing and my inspiration for dealing with ichthyosis. She is now 3 years old and has told me she "wants to be a doctor to make her mommy better!!" She is an excellent student at Playmates Hy Nursery/Preschool, and I am thankful for her teachers, as they, too, are willing to listen and learn about my skin condition.

I have attended five conferences in the United States for people with ichthyosis. There, I met with doctors and met many friends and am able to share my experiences and treatments with others who suffer with NS. These conferences are hosted by the Foundation for Ichthyosis & Related Skin Types (F.I.R.S.T.). F.I.R.S.T. is a non-profit organization which helps people learn more about ichthyosis and other types of skin conditions. Donations are always accepted, because, with money, more research can be done and maybe a cure can be found one day. At these conferences, I have learned many things, too numerous to mention. Great news for us was that neither Brian, my brother, nor D'Jae, my daughter, will pass NS to their children, unless they carry the gene and they get involved with a partner who also carries the gene that carries NS.

My motto: Keep your head up and do not quit. I enjoy volunteering in the community, and teaching and being active at St. John's Church in Pembroke, Bermuda.

The best advice that I can give to people who may be facing challenges in their lives is to tell their story. Knowledge is the best way to get through anything.

If you would like to chat with me personally for help or to add your comments, email me at preciousdjae2003@hotmail.com. I would love to help you, too!!

Diana's story also appeared in her local newspaper, The Royal Gazette, Bermuda's daily newspaper.

In Case of Emergency

In cases of emergency, where you or your child are sick or injured and can't communicate with medical personnel, emergency personnel or police officers will first check you for identification. Adding emergency numbers to the back of your driver's license, insurance card, or personal ID (such as school ID) will help the people involved in your care get to your emergency contact person quickly. Use a blank address label to list your emergency contact numbers on the back of any identification that you carry with you regularly.

Some sources recommend creating an ICE, In Case of Emergency, listing in your cell phone phone book. However, unless a police officer or other witness is available, emergency personnel will not access your cell phone; they will check for a wallet or other source of identification first.

Check with your local ambulance or emergency medical services for cards that you can carry with you that list emergency information and any medications that you take regularly.

Push for Adequate Research Funding Continues

The American Academy of Dermatology Association (AADA) continues to work closely with Congress to ensure adequate funding for research into the causes of and treatments for skin diseases. This year, the AADA has asked Congress to appropriate \$29.27 billion for skin disease research, an increase of \$1.4 billion (5 percent) over last fiscal year. This represents a significant rise in funding in today's tight fiscal environment.

The appropriations bill for Labor, Health and Human Services, and Education, which contains funding for research into skin conditions and their treatments, remains the final appropriations bill the House Appropriations Committee must handle, with delays resulting from the struggle to reach a consensus on whether to raise the minimum wage. Unlike authorizing committees, which establish federal programs and provide for mandatory spending, the appropriations committees handle all discretionary funding requests. Although a solid majority of federal funds are now mandatory in nature (compared with discretionary funding, which comprises approximately one-third of the federal budget), most federally-sponsored medical research is discretionary in nature and is, therefore, appropriated annually by the House and Senate Appropriations Committees.

Funding NIAMS

The National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) would receive just over \$500 million in both the House and Senate versions of the bill. Thanks to the advocacy efforts of the Academy and its allies and to the Burden of Skin Disease Report, members of the appropriations committees recognize the need for increased skin disease research funding. That awareness, however, has not translated into the type of increase that skin disease research advocates feel is necessary. Both the House and Senate Appropriations

Committees have stated their desire to see NIAMS expand the number of diseases being researched and increase partnerships with the research community. The NIAMS Coalition, a group of professional and voluntary organizations (including the Academy) concerned with the works of NIAMS, is planning a fall event targeted to key appropriators in an effort to increase the funding level for the institute.

Funding NIAD

The House and Senate committees have shown considerable disagreement on what is appropriate funding for the National Institute of Allergy and Infectious Disease (NIAD), which also provides funding for skindisease research. The Senate's version of the appropriations bill currently funds the institute at approximately \$.27 billion, which is almost \$113 million less than last year and \$125 million less than the budget requested by the institute. The House version recommends approximately \$4.369 billion, which is inline with the budget request.

The Academy's Federal Affairs staff predicts that it is unlikely that the bills will be finalized prior to the fall elections. However, the Academy will continue to monitor the appropriations bill as it progresses through Congress and will work with the leadership of the House and Senate Appropriations Committees to ensure proper funding. This funding is essential to continue progress in the research and treatment of skin diseases and to reduce the medical, social, and financial burden caused by skin conditions.

Reprinted from Dermatology World, Vol. 16, No.9, September 2006. Dermatology World is a publication of the American Academy of Dermatology Association.

Fifth Annual Patient Art Exhibit

The Society for Investigative Dermatology (SID) is hosting the fifth annual patient art exhibit at its 2007 Annual Meeting in Los Angeles, California. The meeting will take place May 9 through 12, 2007.

The art exhibit is an excellent opportunity for patients to present the impact of skin disease in a personal and creative manner to the researchers committed to finding treatment and cures.



An exhibit release form must be filled out for each submission. The SID will pay to ship the art and have it professionally framed. The piece will be returned to the artist after the exhibit. Please contact Becky Minnillo if you need additional information, 216-579-9340, or Minnillo@sidnet.org.

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SUMMER CAMPS

Camp Wonder 2007

The Children's Skin Disease Foundation is now accepting applications for Camp Wonder 2007, an incredible experience being offered to children with skin disease, ages 7-16, at no cost to the child or family. Camp Wonder is a medically staffed summer camp for children with all skin diseases. At camp, children with skin disease forget about their illness and have fun doing many activities such as arts and crafts, ropes course, swimming, boating, horseback riding or theatre. To register your child for camp please visit www.csdf.org or e-mail Francesca or Christine at campwonder@csdf.org, or call 925-947-3825. We hope to see you this summer!!!

Camp Wonder at Camp Arroyo

Livermore, California
June 24 - June 30, 2007

Camp Wonder at Victory Junction

Greensboro, North Carolina
July 14 - July 19, 2007

The Phantom Tea

Letters for the Foundation for Ichthyosis & Related Skin Types First Annual "Phantom Tea" have been mailed. Invitation requests are coming in from all over the country, meaning "tea parties" are being held across the country as a grassroots effort to raise awareness and funds for ichthyosis.

It is not too late for you to ask family, friends, and coworkers to your Phantom Tea Party. Invitations and tea bags are available from the office.

Camp Discovery 2007

Every year, the American Academy of Dermatology sponsors a week of fishing, boating, swimming, water skiing, arts and crafts, and just plain fun. Under the expert care of dermatologists and nurses, Camp Discovery offers campers the opportunity to spend a week among other young people who have similar skin conditions. Many of the counselors have serious skin conditions as well, and can provide support and advice to campers. Fun, friendship, and independence are on the top of everyone's agenda. Everyone shares in the Discovery of what it's like to be included. There is no fee for camp. Full scholarships, including transportation are provided by the American Academy of Dermatology through generous donations. See www.campdiscovery.org for more information, or www.aad.org - Public Resources / Parents and Kids. Or call the American Academy of Dermatology at 847-330-0230.

Teen Camp

July 7 - 13, 2007 Crosslake, MN
(Ages 15-16)

Junior Camp

July 14 - 20, 2007 Crosslake, MN
(Ages 10-14)

Camp Dermadillo

August 5-10, 2007 Burton, TX
(Ages 9-16)

Camp Horizon

August 11-18, 2007 Millville, PA
(Ages 8-13)

Have you moved recently or are planning on moving soon? Please let us know your change of address so you can continue to receive the Focus. Postage for the newsletter does not include forwarding.



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