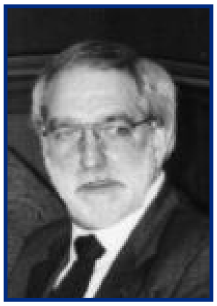
Ichthyosis Focus

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

Vol. 25, No. 1 A Quarterly Journal for Friends of F.I.R.S.T. Spring 2006

Gene for Ichthyosis Vulgaris Found

By Philip Fleckman, MD



A collaboration between an English dermatologist and an epidemiologist defined the more common forms of ichthyosis in the mid 1960's (1). They described ichthyosis vulgaris (IV) as the most common form of ichthyosis (vulgar is the Latin word for common) (2). Using the clinical descriptions they developed, they surveyed a group of English school children and determined that about 1 in 250 people was affected. The investigators looked at skin biopsies of affected individuals and noted an interesting abnormality. The top part of the skin, the epidermis, can be divided into four layers, based on the way it looks under the microscope. The top layer of the epidermis, the cornified layer, is where most of the barrier function of the skin is found and is abnormal in most of the ichthyoses. The granular layer, the layer beneath the cornified layer, is made of tiny granules. In ichthyosis vulgaris, the granular layer is often decreased or absent. The investigators also determined that ichthyosis vulgaris was inherited as a dominant autosomal trait.

In addition to two sex-determining chromosomes, each of us has 22 pairs of “autosomal” chromosomes, one from our mother and the other from our father. Each chromosome pair has two alleles (copies) of a particular gene, one from each parent. We have about 30,000 genes on our chromosomes, each of which determines the nature of a protein by using a “code.” If a mutation (a bad change) in the code for a gene on one of these chromosomes occurs, the protein for which that gene codes is adversely affected. In some cases, a mutation in only one allele results in a disorder. The mutation is said to be “dominant.”

Although mutations underlying most of the ichthyoses have been identified (see, for example, articles in the Spring 2003 and Spring 2005 issues of Focus, available on the F.I.R.S.T. website), the underlying cause of ichthyosis vulgaris has only recently been identified (3). Frances Smith, Irwin McLean, and investigators from Scotland, Ireland, and the U.S. built on previous work to make the discovery.

In the mid 1980's in Seattle, Virgina Sybert (a member of F.I.R.S.T.'s Medical and Scientific Advisory Board, the MSAB), Beverly Dale, and Karen Holbrook, showed that profilaggrin, a protein that makes up most of the granules in the granular layer in human epidermis, was reduced or absent from the skin of individuals with IV. I joined that group soon after, and we showed that the profilaggrin defect in the epidermis was maintained in epidermal cells cultured from the skin of affected individuals and that the gene for profilaggrin was being decoded (transcribed) normally. However, the decoded message that tells the cells how to make the protein profilaggrin was unstable in cultured cells from individuals with IV. We determined that a subset of people with ichthyosis vulgaris had no detectable granular layer. We collaborated with a group at the National Institutes of Health, including Sherri Bale and John DiGiovanna (both members of the MSAB) and John Compton, to study a large family with ichthyosis vulgaris in whom the granular layer was absent in some affected members. We showed that the individuals with IV with no granular layer all had changes

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Register Now!!

2006
National Family Conference
Soaring to New Heights

June 30, July 1 & 2, 2006
Atlanta, Georgia
Deadline for Registration - May 31, 2006
See pages 11-14

Ichthyosis Focus

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The Foundation for Ichthyosis
& Related Skin Types
1601 Valley Forge Road
Lansdale, PA 19446

215.631.1411
800.545.3286
215.631.1413 fax
email — info@scalyskin.org
www.scalyskin.org

Executive Director
Jean Pickford

Editor
Maureen Tierney

Medical Editor
Amy Paller, M.D.

Editorial Assistants
Louis Giuliana
Tiffany Moore

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

Correspondence Corner

To Whom It May Concern:

I became acquainted with your organization a number of years ago when I first experienced hair loss. I am 56 years old and have battled ichthyosis my whole life, though much of that time the medical community focused their attention and treatment on my allergies and eczema. I greatly appreciate your information on skin care and the several hydrating products that I have tried. Keep up the good work!

The purpose of this letter is to pass on a tip on skin care that I discovered quite by accident. In November, my husband and I went to Jamaica on vacation. By that time of the year I begin to have scale build up, especially on my back. When we got to Jamaica, I made it a point to be out in the sun for several hours. Within several days, the scales fell off. I was so impressed! I have always found that my skin improves in the summer time, but this was dramatic. I have even considered going to a tanning salon to see if it will have the same results, but I have not had an opportunity to try it yet.

I hope this tip will help others. Again, I do appreciate all the info you pass on to those of us who struggle in our skin management.

Sincerely,

Sandra Heyburn
Atglen, PA

Medical Editor's Note:

Some of our members report that their skin improves with sun exposure. Some members find that using tanning salons or tanning beds helps to exfoliate their skin scales in the winter months. However, dermatologists have long known that ultraviolet (UV) radiation from the sun or artificial light sources, such as tanning beds and sun lamps, can cause skin cancer. The Department of Health and Human Services has made that official by adding UV radiation to the government's list of known carcinogens.

Speak with your dermatologist about the dangers of UV radiation exposure and some alternative methods for exfoliating your skin. The American Academy of Dermatology website has information about sun exposure and sun safety, www.aad.org.

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Gene for Ichthyosis Vulgaris Found

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that localized to one small region on the long arm of chromosome 1, where the gene for profilaggrin, along with many other genes involved in development of the epidermis, is located.

We looked unsuccessfully for mutations in the profilaggrin gene. The profilaggrin gene is unusually large, and its structure makes it very difficult to study. Drs. Smith, McLean, and colleagues developed a means to sequence the gene and identified mutations that underlie ichthyosis vulgaris. They found that, rather than being a dominant disorder, IV is semi-dominant. Severely affected individuals have mutations in both copies of the profilaggrin gene, while those with mutations in only one copy usually have a very mild skin problem. The number of people in the Scottish, Irish, and U.S. populations studied with mutations in one copy of the profilaggrin gene is high. These findings explain a number of observations in IV: 1) the prevalence of the disease is high, but some are affected much more severely than others; 2) the decrease in the granular layer varies, but a subgroup of individuals with IV have no detectable granular layer and very little detectable profilaggrin in their skin; and 3) the underlying cause of the disorder is located where the gene for profilaggrin is found.

Dr. McLean and his colleagues from Scotland, Ireland, Denmark, and the U.S. have extended these findings recently to include people with atopic dermatitis (eczema) (4). Many individuals with ichthyosis vulgaris also have atopic dermatitis and asthma; about 37-50% of people with IV have atopic dermatitis, and about 8% of people with atopic dermatitis have IV. Many of the people with atopic dermatitis have mutations in the profilaggrin gene, and these appear to be "a frequent transmissible (inherited) predisposing factor in …atopic dermatitis." The theory is that the abnormal barrier function of the epidermis in IV results in atopic dermatitis.

Hopefully, these findings that began over forty years ago will lead to improved treatments and ways to prevent these debilitating disorders.

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Correspondence Corner

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Dear Friends:

I have a six-year-old grandson with lamellar ichthyosis and have a question for those of you who have been through it. What kind of sunscreen do I use for his face? He is extremely sensitive to sunscreens with alcohol in them due to the tiny cracks in the skin, and many of the common brands burn his face. Any ideas would be appreciated. My email address is thingsofcloth@sbcglobal.net

Jennetta Barrow
Muldrow, Oklahoma

Correction

In our last issue, Volume 24, No. 4, Winter 2006, we incorrectly printed the website for Project Save Our Skin (SOS), a non-profit managed by Cort DeHart and Elizabeth Barry to raise money for lamellar ichthyosis research. The correct website address is www.projectsaveourskin.org. We apologize for the error and any confusion it may have caused.

Advocate for Ichthyosis Research

The Foundation's Advocacy Committee has been mapping a plan to make ichthyosis more known and understood in Congress. The first initiative is to educate Congressional representatives about ichthyosis and let them know that constituents in their districts are affected by the disease and more research funding is needed.

Whom do we want to contact?
Members of the U.S. House of Representatives and your two U.S. Senators. To access the information for your location for the House of Representatives, go to www.house.gov and search using your zip code. For the U.S. Senate, go to www.senate.gov and search the state list under *Find Your Senators.*

What do we want to ask for?

1. Ask for support for increased funding for medical research at the National Institutes of Health (NIH).
2. Encourage the NIH to increase skin disease research, specifically, ichthyosis research.

When do we do this?
Now is the time to get to know your representatives and their staff. The Budget process takes place during February 1 through April 15 and the Appropriations process typically works like this:

February - May: Hearings and discussion.
May - September: Real numbers come out.
October 1: Beginning of the new fiscal year.

Where does it all take place?
If you are in Washington, D.C., you can make an appointment to visit your representative's office on Capitol Hill. If not, you can meet with your representative and/or their staff at their local district offices in your area.

How should I contact them?
You can email your representative by visiting www.house.gov/writerep. Other ways to contact your representative are by sending a faxed letter (regular mail may be slow), setting up a personal meeting, talking over the telephone, or submitting written testimony to the House Appropriations Committee on Labor, Health, and Human Services.

Here are the basics:

Introduction: state your name and address, reinforce that you are a voting constituent.
Be prompt, be quick, and be prepared.
Clearly state the "ask": increased medical research funding.
Personalize!!
Bring visuals (ichthyosis fact sheet, pictures).
Follow up.

Basic information for a Congressional visit, a printable fact sheet on ichthyosis, and a sample letter written to Congress are available on our website, www.scalyskin.org. If you do not have access to the Internet, please call Maureen in the Foundation office, 1-800-545-3286, for copies of this information.

The Chair of the Foundation's Advocacy Committee met with Dr. Elias Zerhouni, Director of the National Institutes of Health (NIH) for a briefing on the NIH budget. The important message that came out of that meeting was that members of the Foundation should contact their federal representatives to urge increased funding for the NIH and to emphasize the importance of biomedical research.

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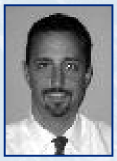

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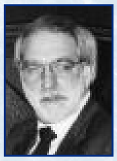

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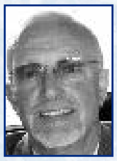

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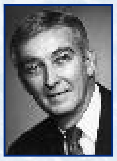

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Executive Director's Report

Dear Members & Friends of F.I.R.S.T.:

Ahhh! The summer months are just around the corner. For many affected people, the summer brings relief to their skin as the higher humidity and moisture lessens the dryness. But as we all know, the summer can also bring the danger of overheating and/or heat exhaustion. Be sure to keep yourself hydrated and cool as you enjoy the warmer weather. Keep in mind, the Foundation has several resources for you, including a free product listing booklet (for members in good standing) listing more 100 products, including lotions, creams, and cooling products and, an overheating fact sheet with creative techniques for keeping yourself cool. As always, if you have any questions or concerns, please don't hesitate to call us at the office.

In early March, I traveled with Maureen Tierney, our Program Director, to San Francisco to meet with our Medical & Scientific Advisory Board for our annual meeting. Each year when we gather for this meeting, I continue to be so impressed and amazed by this group of 25 dermatologists. Not only are they the leading ichthyosis experts in the country, but they all care so deeply for ichthyosis patients and our Foundation. The Board welcomed a new member this year, Dr. Jonathan Dyer. Dr. Dyer is a pediatric dermatologist from Columbia, MO, who volunteered his services at the 2004 family conference in Kansas City.

F.I.R.S.T.'s Medical and Scientific Advisory Board

While in San Francisco, Dr. David Scholl, our Foundation president, met Maureen and I and we visited many pharmaceutical company executives while they exhibited in the Moscone Convention Hall. The purpose of our visits was to strengthen relationships with our pharmaceutical partners and to explore new avenues of fundraising and in-kind donations. The meetings were very successful, and I look forward to significant pharmaceutical support again in the future.

As I reported in the last newsletter, the Foundation has launched its own research program. As of this writing, I am proud to report that the first step of the granting process is completed and we received eight “Letters of Intent.” This means that there are eight researchers who are interested in submitting a full application to the Foundation for funding for ichthyosis-related research. The Foundation does not have enough money to fund all eight, so the competitive process begins. Full applications are due on April 15, and our volunteer Research Review Committee will begin the task of scientific review. I look forward to reporting on this exciting program in the next issue.

A request has been re-submitted to Congress to fund an “Ichthyosis Tools” grant. The grant focuses on creating three tools that are instrumental for ichthyosis research. These tools, which would be available to all researchers, include: 1) genomic clones, 2) immortalized keratinocytes, and 3) mouse models. If you recall, we were unsuccessful in receiving funding for this grant in FY2005. It has been recommended that we resubmit through Senator Arlen Specter's (PA) office. Please make every effort to advocate on behalf of the Foundation and this grant request. See page 4 to learn how you can make a difference on Capitol Hill.

ACCURATE IMAGING

I want to use this forum to recognize publicly Accurate Imaging, Inc., our website hosting company in Teaneck, NJ. Joe DeMicco, CEO, and his staff have generously donated our website hosting and management, including consultation services, site edits, and revisions since 1999. Most recently, Accurate Imaging updated our website's look. We are very grateful for this generous donation. The Internet has introduced our Foundation to many families who otherwise did not have support and reliable information. I encourage everyone to visit their website, www.accurateimaging.com.

In closing, I want to remind everyone that our Spring Membership Renewal Campaign is underway. Recently, you should have received a renewal letter from me describing the benefits of membership and an envelope to return your donation. It is my hope that everyone will renew or reactivate his or her membership and make the Foundation the strongest it's ever been! The Foundation survives on the financial support of our members, so please be generous.

Warm regards,

Jean

Jean R. Pickford
Executive Director

Annual Report Fiscal Year 2005

President's Report

Dear Members and Friends of the Foundation:

I wish to begin my first annual letter by recognizing my predecessor, Laura Phillips. As president from 2001 to 2005, Laura has worked closely with Jean Pickford, our highly effective staff, and her fellow officers and board members to keep F.I.R.S.T. moving forward with our mission: to provide education, service, resources, support and, now, our own research program dedicated to those with ichthyosis and the related skin types. Laura served this mission exceedingly well and, thus, F.I.R.S.T. entered 2006 as vibrant and financially sound as ever with tremendous opportunities in front of all of us! Thanks, Laura.

Fundraising is a key part of maintaining the highest level of service to our members. We are blessed by the hard work and the generosity of so many. Fiscal Year 2005 was another successful year in this regard in many ways.

Member donations and grassroots special events are so critical to meeting our needs. This year's events included the 4th annual Monster Dash in Friendswood, Texas; a car wash held by members of the National Honor Society of Flandreau High School in South Dakota; students selling bracelets at Central Middle School in Grafton, North Dakota; and many other creative ideas from active members across the country. We are continually amazed at the awesome support and energy displayed by so many of all ages for the important work promoted by F.I.R.S.T.

Large benefactor gifts were committed in 2005 for dedicated research activities in EHK, Lamellar/CIE, and ichthyosis-related skin disease (any type), and many repeat, and new corporate donors came through with sizeable gifts. In Quarter 1 2006, we announced a new and exciting partnership between F.I.R.S.T. and Project Save Our Skin (SOS) of Fort Worth, Texas. The brainchild of Cort DeHart and his wife, Elizabeth Barry, after the birth of their daughter, Project SOS and F.I.R.S.T. will join forces to fund a research grant focused on investigating the causes, treatments, and potential cures for lamellar ichthyosis.

Armed with "start-up" funding support, and under the technical leadership of Dr. Leonard Milstone and the administrative support of Maureen Tierney, the Research Committee worked feverishly in 2005 to establish the required elements to launch the Request for Proposals (RFP). Initiating F.I.R.S.T.'s Research Program in Quarter 1 2006 truly represents a watershed event for our members and organization. Grant applications will soon be peer reviewed, and we expect that awardees will be announced at the Family Conference in Atlanta, Georgia (June 30-July 2). Soon, important research projects will be ready to begin in earnest!

The compelling DVD entitled "*Living with Ichthyosis: A Teenage Perspective"* was a major educational tool developed for F.I.R.S.T. in 2005. The DVD was produced by Justin Tormey's large donation of skill and resources (Justin is President of ASAP Productions, New Hope, Pennsylvania), and with a grant from Operation Good Neighbor Foundation to underwrite the costs of production.

The DVD is a powerful story starring eleven very confident, fun-loving young men and women intended to educate young people, parents, and friends about ichthyosis. What stands out, in my view, is how these teens candidly discuss the tough issues they faced growing up with their disease, including topics ranging from skin care techniques, friendships and dating, to participation in extracurricular activities and achieving their future goals. The DVD is a must-see for all and is now available for purchase directly from the Foundation.

The board administration highlight of the year was our November retreat in Philadelphia. The meeting provided all board members the opportunity to interact on the topics of effective fundraising, the Research Program and the policy to govern it, and the development of various programs focused on reaching out to all potential donors through an annual leadership campaign program. Successful fundraising initiatives are necessary to continue the research program that was adopted in 2005 and will be initiated in 2006.

Several board members were recognized for their dedication to F.I.R.S.T. as their terms expired, and one more joined the board as a new member for a three year term. We commend the work done by Dr. Gloria Graham in providing leadership both as a long-term board member and through her role as Chair of the Board Development Committee.

As we embark on several ambitious future goals and celebrate our 25th anniversary, three major events in 2006 serve to highlight our activities, two of which were successfully accomplished in San Francisco in March. First, a fundraising testimonial dinner attended by over 140 colleagues, family,

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Annual Report Fiscal Year 2005

President's Report

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and friends was held to honor the founding role and service to the Foundation provided for so many years by Drs. Mary Williams and Peter Elias. The event raised over $31,000 for F.I.R.S.T. in Mary and Peter's name and was a very nice tribute to two outstanding individuals and partners.

Second, over 20 members of the Foundation's Medical and Scientific Advisory Board met in March to discuss important strategies aimed at reaching out to more clinical and scientific colleagues to increase education and awareness of ichthyosis and to overcome the obstacles that researchers face in translating their findings into useful technology for patients with ichthyosis.

Third, our National Family Conference will be held in Atlanta (June 30 - July 2). The theme of this year's meeting is *Soaring to New Heights*, a theme most appropriate to describe how our board, staff, advisors, and sponsors feel about the Foundations' prospects for future success!

In closing, F.I.R.S.T. has accomplished many good things through the wonderful deeds of many good people over the past 25 years. With the continued strong support of our members, friends of the Foundation, corporate sponsors, staff, and board members, F.I.R.S.T. is well positioned to provide greater assistance and service to people with ichthyosis and related skin types for years to come! We look forward to working jointly with you to exceed our goals in 2006.

Sincerely,

David R. Scholl, Ph.D.
President

Chief Financial Officer's Report

Dear Members and Friends:

I am pleased to report that the financial condition of your Foundation continued to strengthen during the past year. Once again, our auditors have given us what accountants call an unqualified opinion. In English, that means all is well in our house. As one of your new board members and new Chief Financial Officer, one of my primary goals will be to help guide the Board of Directors in applying the same sound financial principals that have made the Foundation what it is today. Certainly, with the increased focus on research funding and the related fundraising programs to support those efforts, we all will be kept quite busy.

Since this is my first year as CFO, I took the opportunity to come a day early to our board retreat this past November. I used the extra time to visit the executive offices and see how our staff performs their daily magic looking after the Foundation. I also went with Jean Pickford to meet the partner and staff at the certified public accounting firm responsible for doing our audit, so that I could obtain their opinions about how we operate. As it turns out, the firm does quite a few audits of not-for-profit organizations in our area and they were very complementary about how Jean and her team carry out a multitude of tasks.

As you can see by the Statement of Financial Position from our audited financial statements included in this issue of Focus, significant improvements have been made to our financial condition. To begin with, cash and marketable securities have increased by just over 50%. To protect these funds, there is a Board-established policy that requires regular timely reviews by the finance committee to insure that investments are in compliance with investment guidelines. I have been in the process of updating our investment policy to accommodate the increase in funds and maximize the return on them while maintaining a very safe margin of exposure. Although net equity only increased by 22.4%, unrestricted equity increased by 73.5% which is a major leap in reaching

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Chief Financial Officer's Report

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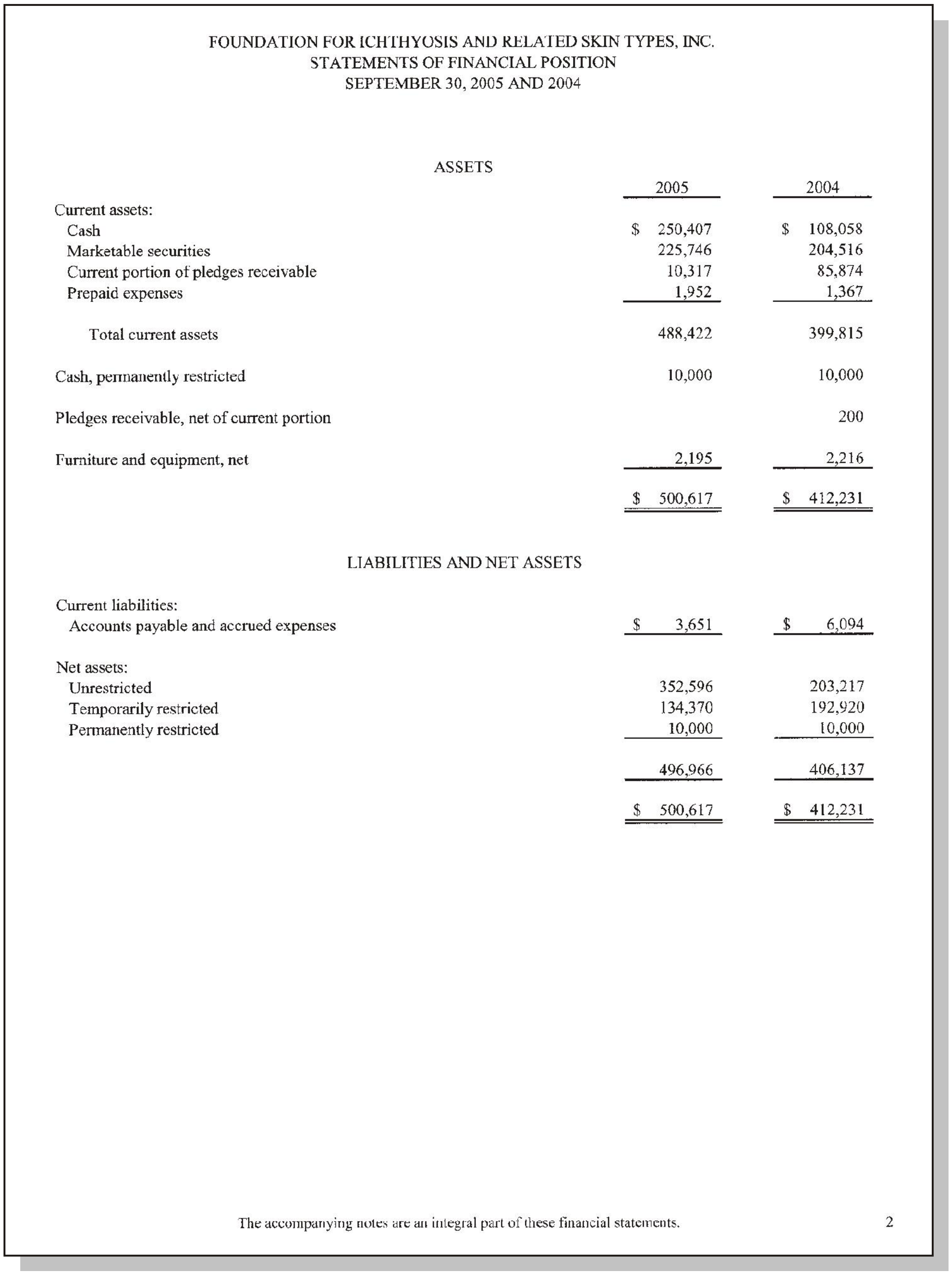
for financial security. More specifically, our unrestricted equity can provide for 1.3 times our annual operating expenses (not including research funding) based on the 2006 expense budget.

From a revenue standpoint, we had a decrease of 17% in contributions primarily due to receiving $85,000 less for Donor Designated Research in 2005 as compared to 2004.



FOUNDATION FOR ICHTHYOSIS AND RELATED SKIN TYPES, INC.
STATEMENTS OF FINANCIAL POSITION
SEPTEMBER 30, 2005 AND 2004

ASSETS

	2005	2004
Current assets:		
Cash	$ 250,407	$ 108,058
Marketable securities	225,746	204,516
Current portion of pledges receivable	10,317	85,874
Prepaid expenses	1,952	1,367
Total current assets	488,422	399,815
Cash, permanently restricted	10,000	10,000
Pledges receivable, net of current portion		200
Furniture and equipment, net	2,195	2,216
	$ 500,617	$ 412,231

LIABILITIES AND NET ASSETS

	2005	2004
Current liabilities:		
Accounts payable and accrued expenses	$ 3,651	$ 6,094
Net assets:		
Unrestricted	352,596	203,217
Temporarily restricted	134,370	192,920
Permanently restricted	10,000	10,000
	496,966	406,137
	$ 500,617	$ 412,231

The accompanying notes are an integral part of these financial statements. 2

Although this affects the amount we can use to fund research, it fortunately does not affect our ability to fund programs, pursue fundraising initiatives, and keep the office operational. From an expense standpoint, everything came in pretty close to budget ending in an overall 6% reduction of expenses.

Looking towards the remainder of the year and thereafter, I think the Foundation will be experiencing some exciting times. Most importantly, we are developing the ability to fund significant research. To continue this development and broaden our horizons so that future generations may be helped, we need all of your help. Jean Pickford has told the Board about how many of our members have already been successful in initiating local campaigns or soliciting individuals looking for a worthwhile cause to which they could direct some of their donations. As the Board looks for new ways to increase fundraising efforts, try to think of ways to help in your community. On a closing note, if anyone has an idea they might want to pursue or a person to solicit, please send the office an e-mail, info@scalyskin.org, or contact Jean at 1-800-545-3286, and we can provide some help in how to approach the effort.

Sincerely,

John J Schoendorf

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, 2005. 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 215-631-1411, or 1-800-545-3286.*

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Diane Mencia
Mercer Management Consulting
Jennifer Millican
Gary Mills
Alan Milstone
Patricia Mondi
Leslie Moody
Kathleen Moran
Frank Mosunic
Edith Murphree
Richard & Joan Murphy
National Organization for Rare Disorders
Joan Neaton
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Genevieve Robin
Kathryn Rogers
Linda Rogers
Elisabeth Rogers
Athar Saeed
Liza Santamina
Arthur Sawyer
Stephanie Sawyer-Ames
Virginia Scully
David & Linda Schell

2005 Contributors List

Mary Schwartz
Eric Schweighoffer
Michael Scirica
Jennifer See
Kathleen M. Shanahan
Christopher Short
Michael Sisack, MD
Peter Stano
Marvin Stark
Thomas Stuelpnagel
Rita Tanis
Dawn & Michael Teply
Janie Thompson
Patricia Tierney
Melissa Tierney-Osterloth
Norma Treat
Theresa Tremmel-Anderson
United Way Bartholomew County
United Way Fox Cities, Inc.
United Way Trident
United Way Services Cleveland
Janice & Sam Unruh, Jr.
Martha Van Zile
Valerie Vitali
Charles & Judy Wagner
Leah Wanke
Sharon Waters
Mark Weber
Diane White
Karen Wolkin
Lonnia York
Deborah Young
Arnold L. Zimmerman
Marilyn Zinn
Jennifer Zubler-Schoenl
Eric Zugerman

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Ann Benedetto
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BP Amoco
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Edison International
Mary Fitzpatrick
Karoline Freed Biggs
Susan Haberman
Wood Hull
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In Honor of Macy Rogers' Birthday
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Lisa Kass
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Alan & Jennifer Leblang
Grace McMillian
Dr. Laurence Miller
Vivian Milstone
National Honor Society of Flandreau, SD, High School
Marcia & Tim Ohlwiler
Mary Alice Ponzo
Jo Potestivo
Tracie Pretak
Joseph Proscia
David & Anna Purcell
Gabriele Richard, MD
H.G. & Barbara Sawyer
Elliot & Phyllis Shulman
Nanette Silverberg
Larry & Brenda Staton
Theraplex Company
Scott R. Thompson
George T. Underhill
United Way - Whatcom County
Wachovia Foundation
Sammy Williams

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CFC - Greater Twin Cities
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Ashley Duchossois Joyce
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John Jessiman
JSJ Pharmaceuticals, Inc.
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Society for Pediatric Dermatology
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Beiersdorf
Frances Blankis
Henry Bukaty
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Lucinda Dudley
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L'oreal USA, Inc.
Michael A. Miller
Leonard & Ellen Milstone
Tiffany Moore
Ortho Neutrogena
Amy Paller, MD
Richard Pedtke
Eustolia Perez
Laura & Chris Phillips
Ramona Schiller
John J. Schoendorf
David & Valerie Scholl
Robert Seaman
Charles T. Sides, Jr.
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Dermik Labs/Aventis
Merz Pharmaceuticals
Monster Dash Grassroots Event
Eugene Van Scott, MD

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Michael Briggs
ePharma Learning, Inc.
Kober Golf Outing Grassroots Event
NeoStrata Company
Operation Good Neighbor
Gary Price
Peyton & Janet Weary

$50,000+

UPS Foundation

2006 National Family Conference: ***Soaring to New Heights!***
June 30, July 1 - 2 ♦ Crown Plaza Ravinia Hotel ♦ Atlanta, Georgia

PROGRAM AT-A-GLANCE

Friday, June 30th

(pre-scheduled clinical screening appointments throughout the day)

12 — 2 pm	Registration
2—4 pm	General Session
4—4:15 pm	Break
4:15—5:30 pm	Workshops I
6—9 pm	Family "Picnic" Social (optional)

Saturday, July 1st

7—9 am	Breakfast Buffet
9—12 pm	Workshops II
12—1:30 pm	Lunch
1:30—3 pm	Disease-Specific Discussions
3—3:15 pm	Break
3:15—5:30 pm	Practical Advice Discussions
6—10 pm	Dinner Social

Sunday, July 2nd

7— 9 am	Breakfast Buffet
9—11:30	Group Support Networking
11:30—12:30 pm	General Session/Conference Wrap-Up
12:30—	Farewell Lunch (Optional)

Registration: To register for the conference, complete the Conference Registration Form and submit payment to the national office by May 31. If you need to cancel prior to the conference, a full refund will be awarded. Registration will not be complete without form and payment.

Meals: Breakfast, lunch, and dinner on Saturday and breakfast on Sunday are included in your registration fee. Friday evening's dinner and Sunday afternoon's lunch are optional for each attendee and must be pre-paid with your registration.

Dress Code: Conference attire is casual, including Saturday evening's dinner.

Clinical Screening: All affected individuals have the opportunity to meet with leading expert physicians in ichthyosis for free, private 10-minute consultations on Friday, June 30. Participation is voluntary. Sign-up is required prior to the conference. If you are interested, you must complete Section V of the Conference Registration Form.

Child Care: A professional child care company will provide services during workshops for affected and unaffected children, ages 1-8.

Teens & PreTeens: There will be a separate program for children ages 9 - 17, focused specifically on age-appropriate activities and discussions.

2006 National Family Conference: *Soaring to New Heights!*
June 30, July 1—2 ♦ Crown Plaza Ravinia Hotel ♦ Atlanta, Georgia

Hotel Accommodations - The discounted room rate negotiated with the hotel is $94.00 plus applicable taxes, per night, flat occupancy. For those who want to extend their stay in Atlanta, these rates are available 3 days prior to and post the official conference dates.

All attendees must make their own reservations at the Crown Plaza Ravinia. Call toll-free at 800.554.0055 or 770.395.7700. To ensure you receive the discounted conference room rate, you must identify our group name of "Foundation for Ichthyosis & Related Skin Types." Should you fail to identify yourself with our group, the room rate quoted will apply and no adjustments will be made after your arrival. Reservations must be received on or before *June 7, 2006.* All reservations must be accompanied by a first night room deposit guaranteed with a major credit card.

Travel from Airport to Hotel - The Crown Plaza Ravinia is approximately 27 miles from the Hartsfield/Jackson International Airport.
Taxi - Travel from the airport to the hotel is approximately $50.00. Travel time is 35 minutes.
Train - The hotel stop on the Atlanta public train system, MARTA, is called N9 Dunwoody Station, which is .3 miles from the hotel. The travel time from the airport is 40 minutes, and a one-way fare per person is $1.75 for any stop on the system. The hotel provides a complimentary shuttle between the Dunwoody Station and hotel. For train schedules, visit www.itsmarta.com.

The hotel offers a complimentary shuttle service within a 3-mile radius of its location.

Airline Travel to Atlanta
The Foundation has contracted with AirTran Airways and American Airlines to offer discounted air travel to conference attendees:

AirTran Airways EventSavers Program - AirTran will provide a 10% discount on the lowest available AirTran Airways one-way fare. Attendees may travel three (3) days prior to the conference and three (3) after the conference. Other rules and restrictions apply. Contact the AirTran Airways EventSavers Program at 1.866.683.8368 from 8 am to 9 pm EST weekdays to book your air travel. Please refer to event code: ATL063006.

American Airlines - American will provide a 5% discount on applicable fares for travel dates to Atlanta between June 27 and July 6, 2006. Other rules and restrictions apply. For reservations, contact their Meeting & Services Desk at 800.433.1790 between 5 am and 11 pm CST and refer to code #A0966AQ.

National Patient Travel Center - You may be eligible for free transportation using the Angel Flight America Program. If you live within 1000 miles of Atlanta, Georgia, Angel Flight will fly a family in a 4-seater or 6-seater plane to and from the conference at no cost. Contact the National Patient Travel Center at 888.675.1405 and refer to the 2006 Foundation for Ichthyosis Family Conference Special Lift Program.

Driving Directions to Hotel - Contact the Crown Plaza Ravinia at www.cpravinia.com or call their hotel staff at 770.395.7700. Parking is complimentary at the hotel.

Kindly mail completed registration form and payment by **May 31st** to FIRST, 1601 Valley Forge Road, Lansdale, PA 19446. If you have any questions, please call 800.545.3286 or email at info@scalyskin.org.

2006 National Family Conference: ***Soaring to New Heights!***
June 30, July 1—2 ♦ Crown Plaza Ravinia Hotel ♦ Atlanta, Georgia

Section I - Contact Information (please print clearly)

Name: ____

Address: ____

City: ______________________ State: ______ Zip: _________ Country: ____________

Phone (Day): _________________________ Phone (Evening):___________________________

Cell Phone: _________________________ Email: ________________________________

Section II - Registrant's Information (Please print clearly; nametags will be provided.)

This section must be completed with registrant's complete name, age, and type of ichthyosis (if appropriate). There are four tracks of programs: Adult (age 18+), Teen (ages 13-17), PreTeen (ages 9-12), and Child (ages 1-8). Based upon ages provided, each registrant will be assigned to the appropriate program.

First Name	**Last Name**	**Age**	**Type of Ichthyosis**

Section III - Child Care Registration

The Foundation has hired a professional child care company to entertain and supervise affected and non-affected children, ages 1-8, while parents/guardians are participating in the adult program. There is a nominal, one-time fee of $15 per child to guarantee placement in the program and to hire the appropriate number of caregivers for the safety of your children.

Name of Child	**Age**	**Type of Ichthyosis**	**List Any Medical Conditions or Allergies**

Section IV - Volunteering

Please check if you would be willing to volunteer some time:
______Assembling Gift Bags on Thursday, June 29
______Chaperoning the teen & preteen groups on field trips, etc.

Volunteer Name: ____________________
____
Phone: ________________________

Registration Form Continued on Next Page

Section V - Clinical Screening Appointments

This is an opportunity to meet with expert dermatologists who specialize in ichthyosis to answer any questions or concerns that you may have. These appointments will take place throughout the day on Friday, June 30, from 9:00 am - 5:30 pm (the first day of the conference). You will be notified prior to the conference of your scheduled appointment time at the contact information provided on page 1.

Name of person for appointment	Age	Male/Female	Type of Ichthyosis	Confirmed by a Dermatologist?
____________________	______	__________	____________	Yes No
____________________	______	__________	____________	Yes No

____Please check here if you prefer an afternoon appointment because of your travel distance. We will do our best to accommodate your request. However, the number of attendees requesting appointments is always very high, so we cannot guarantee an afternoon appointment.

Section VI - Other (please circle yes or no)

Does the Foundation have permission to take photos of your family during the conference? **Yes** or **No**

Does the Foundation have your permission to publish photos of you and your family on office materials, including our website and newsletter? **Yes** or **No**

Does the Foundation have your permission to include all your contact information on the conference roster, which will be distributed to all registrants? **Yes** or **No**

Have you ever attended a conference before? **Yes** or **No**

Section VII - Payment Information

The Foundation has received several sponsorships, which allows us to offer a discounted registration fee of $105 per adult and $60 per child. The actual cost per person to attend the conference is $175. Your conference fees help offset the cost of food, beverages, supplies, etc.

Step 1. Conference Registration Fees

# of Adults Attending (18 or over) ______________ x $105 = _________________
# of Children Attending (17 or under) ______________ x $60 = _________________

Step 2. Child Care Registration (ages 1-8)

# of Children (be sure to complete Section III) ________ x $15 = _________________

Step 3. Family "Picnic" on Friday evening (optional)*

# of Adult Meals (10 or over) _______________ x $20 = _________________
# of Children Meals (9 or under) ______________ x $10 = _________________

Step 4. Farewell Lunch on Sunday afternoon (optional)*

# of Adult Meals (10 or over) ______________ x $20 = _________________
# of Children Meals (9 or under) ______________ x $10 = _________________

Step 5. Grand Total

$

___My check is enclosed, made payable to FIRST, in US funds.
___Please charge my credit card: Mastercard, Visa, American Express (circle one)

Credit card Number: __________________Expiration:_____Authorized Signature: _________________

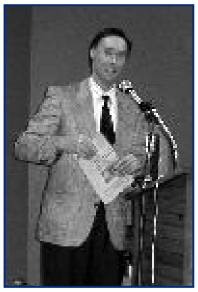
*The Foundation is offering two optional social functions at an additional cost per person. These are optional events and are not included in the conference registration fee.

2006 Testimonial Dinner

Honoring Drs. Mary Williams & Peter Elias

Mary Williams and Peter Elias

On March 3, 2006, more than 175 people gathered at the Delancey Street Town Hall, overlooking the San Francisco Bay, to honor two exceptional dermatologists whose professional careers have been instrumental in the success of this Foundation. Dr. Mary Williams and her husband, Dr. Peter Elias, have devoted their careers to helping ichthyosis patients and founded the organization twenty-five years ago. In 1981, Mary and Peter, along with several affected patients, formed the National Ichthyosis Foundation. Over the past twenty-five years, the Foundation has gone through many changes and much growth, with Mary and Peter helping us all along the way.



Jim Griffin

The event was nothing short of amazing. Family members, friends, colleagues, former fellows and staff, and corporate friends enjoyed a night of humorous and heart-warming stories about Mary and Peter. The most memorable speech was given by Jim Griffin, a long-time member affected with lamellar ichthyosis. Jim was a patient of Mary's and was very involved in the Foundation in the early days. In his speech, Jim shared how his life has been forever changed by Mary and Peter and his involvement with F.I.R.S.T. His message was echoed by all of the other speakers and guests.

When Mary and Peter agreed to be honored, they were extremely humbled by this recognition, but their main objective was to help individuals and families affected with ichthyosis by raising money to support the mission of F.I.R.S.T. I am proud to say they outdid themselves! More than $31,000 was raised in net proceeds. Congratulations to Mary and Peter and all your accomplishments on behalf of the ichthyosis community.

Special thanks to our corporate sponsors:

Ceragenix & Osmotics

University of California, San Francisco

Barrier Therapeutics

Congratulations

to **F.I.R.S.T.** and

Drs. Mary Williams and Peter Elias

on a successful

Testimonial Dinner fundraiser.

We applaud your efforts and

dedication to the ichthyosis community.

Barrier Therapeutics

Turning Science into Practice

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.

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

F.I.R.S.T.
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Lansdale, PA 19446

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