



# NEWSLETTER



PSF Patron,  
Actor John Hurt

...finding the cause, discovering a cure,  
supporting individuals with this rare genetic disorder

## May 2008

**Proteus Syndrome Foundation**

8485 Dulwich  
Cordova, TN. 38016

USA

[www.proteus-syndrome.org](http://www.proteus-syndrome.org)

Andrea Larrondo Marin  
December 22, 2007

Andrea passed on December 22, 2007 she was 15 years old. Every single person who met Andrea will miss her dearly. Her memory will always be alive to those of us lucky enough to have known her. Our

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## Proteus Syndrome Family Conference

Save the Date 2008

October 2 evening meet and greet

October 3-4th full day conference

### Topics to be discussed

- † Orthopedic Conference Discussion
- † Small groups with the professionals
- † Professional Updates on Proteus syndrome
- † Question and Answer sessions
- † Family groups

You will receive a postcard invitation to the conference in the mail by July. At that time if you are interested in attending the conference then return the postcard and you will receive a registration packet in the mail.

### Our Mission Statement

The Proteus Syndrome Foundation is a voluntary not-for-profit organization dedicated to providing family support in the form of education and networking individuals living with Proteus syndrome with other families and medical professionals.

We are also dedicated to raising money to provide far reaching professional health education with our ultimate goal of finding cause, treatments, and the cure for Proteus syndrome.

## Medical Advisory Board

### M. Michael Cohen, Jr., DMD, Ph.D., FCCMG

Professor of Oral & Maxillofacial Pathology  
Professor of Pediatrics  
Dalhousie University  
Halifax, Nova Scotia

### Leslie Biesecker, M.D.

Genetic Disease Research  
Branch,  
National Human Genome  
Research Institute,  
National Institutes of Health,  
Bethesda, MD

### Debra L. Collins, M.S.

Division of Genetics  
University of Kansas  
Medical Center  
Kansas City, KS.

### Joyce Turner, M.S.

Genetic Counselor  
National Human Genome  
Research Institute  
National Institutes of Health  
Bethesda, MD 20892-1253  
jturner1@mail.nih.gov

### R. Neil Schimke, M.D.

Dir. Of Endocrinology,  
Metabolism & Genetics  
University of Kansas  
Medical Center  
Kansas City, KS.

### R. Sid Wilroy, Jr., M.D.

Professor of Pediatrics  
University Of Tennessee  
Memphis, TN

## Board of Directors

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Barbara King

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### Law

### International Affiliates:

Tracy Whitewood óNeal, -  
Chairperson & Parent Con-  
tact, UK  
Amanda Wilson ó Secretary,  
UK

### Secretary

Julia DeLoach

### Grant Strategist and

### Family Support

Kathleen DeLoach

Families are receiving with this newsletter the recently published article:

### **Parenting Children with Proteus Syndrome. Experiences With, and Adaptation to, Courtesy Stigma.**

By Joyce Turner, Barbara Biesecker, Jennifer Leib, Leslie Biesecker, and Kathryn Peters.

This article deals with the experiences a person has who does not have Proteus syndrome or other over-growth syndromes due to their relationship with a person living with such a condition.

We will also publish this article on our website.

## Foundation Yearly Membership

**\$25.00 annual family membership**

**\$35.00 annual professional membership**

### **Mail to:**

PSF

c/o Barbara King, PSF Treasurer  
8485 Dulwich  
Cordova, TN 38016 USA

**These dues are to help support the cost of running the Proteus Syndrome Foundation. We ask you to contribute these dues once a year.**

*These dues are voluntary & not intended to cause any hardship to families.*



## Revised Proteus Syndrome Diagnostic Criteria

### General criteria

All of the following

- † Mosaic distribution of lesions
- † Sporadic occurrence
- † Progressive course

### Specific criteria

Either: Category A or,  
Two from Category B or,  
Three from category C

### Category A

Cerebriform connective tissue nevus (a)

### Category B

1. Epidermal nevus
2. Asymmetric disproportionate overgrowth (b)
  - One or more
    - a. Limbs
      - Arms/legs
      - Hands/feet/digits
      - Extremities
    - b. Hyperostoses of the skull
    - c. Hyperostosis of the external auditory meatus
    - d. Megaspondylodysplasia
    - e. Viscera
      - Spleen/thymus
3. Specific tumors before 2nd decade
  - One of the following
    - a. Ovarian cystadenoma
    - b. Parotid monomorphic adenoma

### Category C

1. Dysregulated adipose tissue
  - Either one
    - a. Lipomas
    - b. Regional lipohypoplasia
2. Vascular malformations
  - One or more
    - a. Capillary malformation
    - b. Venous malformation
    - c. Lymphatic malformation
3. Lung cysts
4. Facial phenotype (c)
  - All
    - a. Dolichocephaly
    - b. Long face
    - c. Downslanting palpebral fissures and/or minor ptosis
    - d. Low nasal bridge
    - e. Wide or anteverted nares
    - f. Open mouth at rest

From Turner et al (2004)

To make a diagnosis of Proteus syndrome, all general criteria and various specific criteria must be satisfied.

- (a) Cerebriform connective tissue nevi are skin lesions characterized by deep grooves and gyrations as seen on the surface of the brain.
- (b) Asymmetric, disproportionate overgrowth should be carefully distinguished from asymmetric, proportionate overgrowth.
- (c) The facial phenotype has been found, to date, only in Proteus patients who have mental deficiency, and, in some cases, seizures and/or brain malformations.

## Research Program

# K v ø u " v k o g " h q

If you would like an opinion about a specific problem with Proteus syndrome, confirmation of the diagnosis of PS, or would be interested in taking part in the research at the National Institutes of Health you will need to provide the following information regarding your child (or yourself if an adult with PS).

- ◁ Description of the existing problems
  - ◁ Medical history
  - ◁ Any operations
    - ◁ Photos
  - ◁ A geneticists report

**Send information to:**

**Julie Sapp**

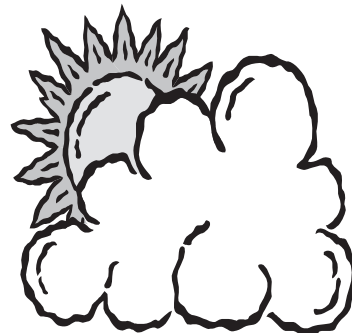
**NHGRI/NIH, BLDG. 10, Room  
3C710**

**10 Center Dr.**

**Bethesda, MD 20892**

**Email: [sappj@mail.nih.gov](mailto:sappj@mail.nih.gov)**

**Phone: 301-435-2832**



## Keeping up with Jeffrey!

I'm going to make a quick review:

My mom and I have been seven months here in the United States again after spending close to three long wonderful months in Colombia spending time with all my family after not seeing them after 7 years.

Now we have the sad and good news the sad news is because my mom has to have an biopsy on her left side of her breast since a year ago she had a surgery sadly her breast imaging the result was problems with her breast.

The good news are that we are in the waiting for my graduation of High School I'm very close two months away till I graduate my graduation will be June 13 in my BOCES (my educational school) where I study Graphic/Web design in computers and still being in that field since I was in 9th grade, and my High School the graduation is June 28th.



We are going to go back to Colombia September 4th we are getting ready so I can do my college there since sadly college here is way to expensive. Since here I cannot work because my Visa Status and other wise I would not be able to pay my own college or at least to help my mom to pay bills or the rent. And we also would like to try new places new horizon new everything. Hopefully after I come back to the US would be after I graduate from college in Colombia and move up here and live here and go to Colombia on vacation.

Another great news are last past March 7th my sister had another child his name is name is Mateo it's my mom's 3rd grandson and of course my 1st Nephew so we are very happy and excited to go back to Colombia and start "fresh" and new everything.

I know that It don't matter where we go or are in this world God will always bless us with a lot of stuff and put angels in our way like you Ms. Kim Hoag , Mrs. Barbara King and the rest of P.S.F. members.

God will never leave us in a bad situation or anything like that.

God bless you all & Thank you  
Jeffrey M. Ortega & Alicia Ortega



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Too many people put off something that brings them joy just because they haven't thought about it, don't have it on their schedule, didn't know it was coming or are too rigid to depart from their routine.

I got to thinking one day about all those women on the Titanic who passed up dessert at dinner that fateful night in an effort to 'cut back the calories'. From then on, I've tried to be a little more flexible !!

How many women out there will eat at home because their husband didn't suggest going out to dinner until after something had been thawed? Does the word 'refrigeration' mean nothing to you?

How often have your kids dropped in to talk and sat in silence while you watched 'Who wants to be a millionaire' on television?

I cannot count the times I called my sister and said, 'How about going to lunch in a half hour?' She would gas up and stammer, 'I can't. I have clothes on the line. My hair is dirty. I wish I had known yesterday, I had a late breakfast, It looks like rain.' And my personal favorite: 'It's Monday.' She died a few years ago. We never did have lunch together.

Because we cram so much into our lives, we tend to even schedule our headaches. We live on a sparse diet of promises we make to ourselves when all the conditions are perfect!

We'll go back and visit the grandparents when we get Steve toilet-trained. We'll entertain when we replace the living-room carpet. We'll go on a second honeymoon when we get two more kids out of college.

Life has a way of accelerating as we get older. The days get shorter, and the list of promises to ourselves gets longer. One morning, we awaken, and all we have to show for our lives is a litany of 'I'm going to,' 'I plan on,' and 'Someday, when things are settled down a bit.'

When anyone call s my 'seize the moment' friend, she is open to adventure and available for trips. She keeps an open mind on new ideas. Her enthusiasm for life is contagious. You talk with her for five minutes, and you're ready to trade your bad feet for a pair of roller blades and skip an elevator for a bungee cord.

My lips have not touched ice cream in 10 years. I love ice cream. It's just that I might as well apply it directly to my stomach with a spatula and eliminate the digestive process The other day , I stopped the car and bought a triple-decker. If my car had hit an iceberg on t he way home, I would have died happy.

Now...go on and have a nice day. Do something you WANT to.....not something on your SHOULD DO list. If you were going to die soon and had only one phone call you could



make, who would you call and what would you say? And why are you waiting?

Make sure you read this to the end; you will understand why I sent this to you

Have you ever watched kids playing on a merry go round or listened to the rain lapping on the ground? Ever followed a butterfly's erratic flight or gazed at the sun into the fading night? Do you run through each day on the fly? When you ask 'How are you?' Do you hear the reply?

When the day is done, do you lie in your bed with the next hundred chores running through your head? Ever told your child, 'We'll do it tomorrow.' And in your haste, not see his sorrow? Ever lost touch? Let a good friendship die? Just call to say 'Hi'

When you worry and hurry through your day, it is like an unopened gift....Thrown away. ... Life is not a race. Take it slower. Hear the music before the song is over.

'Life may not be the party we hoped for... but while we are here we might as well dance!'

Submitted by Meryl Kirwin ô Sebastian's Mom

Dear Families;

Last fall at the family conference we began an effort to compile a medical directory of physicians around the country who have had first hand experience with Proteus syndrome. Thank you to those who have provided names and information of doctors who they have consulted with. Each of the doctors listed has agreed to be included on our referral list. We appreciate their interest in PS and continued support.

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date the list. Our intention is to continually add names of doctors and clinics who have been involved with our PS families in all related specialties. This medical directory can become a valuable resource for all of our PS families. We hope it will continue to expand.

Please send physician names and referrals to Carol Romanoff.

Carol Romanoff  
55 Byram Ridge Road  
Armonk, NY 10504  
924.273.9115  
cbromanoff@optonline.net



## Proteus Syndrome Foundation Medical Resource Directory June 2007

### California:

John R. Moreland, MD                      Orthopedic Surgery  
UCLA Medical Center  
Assistant Clinical Professor of Orthopedic Surgery  
2001 Santa Monica Blvd.  
Santa Monica, CA 90404-2101  
310-453-1911

Jeffrey Eckhart, MD                      Orthopedic Surgery  
UCLA Santa Monica Orthopedic Center  
Professor, Orthopedic Surgery Director,  
310-319-1234

*Birthmarks and Vascular Anomalies Center*                      Interdisciplinary clinic  
UCSF . Univ. of Calif., San Francisco, CA  
1701 Divisadero St., 3<sup>rd</sup> floor  
San Francisco, CA 94115

Ilona J. Frieden, MD Prof. of Clinical Dermatology and Pediatrics                      *Pediatric Dermatology*

William Hoffman                      *Plastic Surgery*

Chris Dowd                      *Interventional Neuroradiology; Pediatric Otolaryngology*

Kristina Rosbe

Mahesh Mankani                      *Plastic Surgery*

Marion Koerper                      *Pediatric Hematology/Oncology*

Isaac Neuhas                      *Dermatologic Surgery*

Amy Gilliam                      *Pediatric Dermatology*

Louis Crotwell RN, nurse coordinator:  
Phone: 415-353-7823  
Fax: 415-353-7478

### **GEORGIA:**

S. Leslie Bertrand, MD                      Pediatric Orthopedics  
Chief, Pediatric Orthopedic Service  
Associate Professor of Orthopedic Surgery  
MCG Health System  
1447 Harper Street  
Ambulatory care Center · 2nd Floor  
Augusta, GA 30912  
706-721-2741

**GEORGIA cont:**

Charles G. Howell, MD Pediatric Surgery  
Professor of Pediatric Surgery  
MCG Health System  
1447 Harper Street  
Augusta, GA 30912  
706-721-3941

Mark Lee, MD, PhD, F.A.C.S Pediatric Neurosurgery  
Clinical Service Chief, Neurosurgery  
Co-director and Surgical Director, Neuroscience  
Center  
Chief, Pediatric Neurosurgery Service  
MCG Health System  
1447 Harper Street  
Ambulatory Care Clinic - 4th Floor  
Augusta, GA 30912  
706-721-4581

Chris Wixon, M.D. Vascular Surgery  
Memorial Medical Hospital  
4700 Waters Avenue  
Savannah, GA 31404-6220  
912-350-8000

**ILLINOIS:**

Amy Paller, MD. Pediatric Dermatology  
Professor and Chair, Pediatric Dermatology  
Northwestern University  
312-695-3721  
apaller@northwestern.edu

Also at: Glenbrook in Glenview IL 773-327-3446

**MASSACHUSETTS:**

The Vascular Anomalies Center Interdisciplinary  
Clinic  
300 Longwood Avenue, Fegan 3  
Boston, Ma 02115  
Kimberly Chalache - Admin Assist.  
617-355-5226  
Vascular.account@childrens.harvard.edu

John Mulliken, MD Plastic Surgery  
Judah Folkman, MD Vascular Biology  
Steven Fishman, MD General Surgery  
Giannoula Klement, MD Hematology/Oncology  
Marilyn Liang, MD Dermatology  
Ahmad Alomari, MD Interventional Radiology  
Gulraiz Chaudry, MD Interventional Radiology  
Darren Orbach, MD Interventional Radiology  
Horacio Padua, MD Interventional Radiology  
Harry Kozekewich, MD Pathology  
James Kasser, MD Orthopedics

James Upton, MD Plastic Surgery  
Mary Beth Sylvia Certified Family Nurse Practitioner  
**MASSACHUSETTS cont.**  
Erin Ryan Certified Nurse Practitioner

**MICHIGAN:**

Elisabeth M. Petty Internal Medicine and Genetics  
Associate Dean · Student Programs  
Associate Professor of Internal Medicine and Human Genetics  
Division of Molecular Medicine and Genetics  
University of Michigan Medical School  
109 Zina Pitcher Place  
2053 BSRB, Box 2200  
Ann Arbor, MI 48109-2200  
734-763-2532

**NEW YORK:**

Maria C. Garzon, MD Pediatric Dermatology  
Associate Professor of Clinical Dermatology and  
Clinical Pediatrics  
Columbia University, NY  
Director, Pediatric Dermatology Morgan · Stanley  
212-305-5293  
Pediatric Dermatology Nurse Coordinator · Diane  
Concannon RN 212-342-3646

Mark R. Sultan, MD, F.A.C.S. Plastic and Reconstructive Surgery  
1100 Park Avenue  
New York, NY 10128  
212-360-0700

Kwaame Anyane-Yeboah, MD Genetics  
Professor of Clinical Pediatrics  
Division of Genetics · CHN6-601A  
Presbyterian  
Columbia University  
3959 Broadway  
New York, NY 10032  
212-305-6731

Carol Lederman, MD Clinical Hematology  
2 Longview Avenue  
White Plains, M.Y. 10601  
914-684-2279

Be the change you want to see in the world  
join the PSF

## Sunshine Society

The Proteus Syndrome Foundation would like to thank all family and friends who have honored this organization by putting the Proteus Syndrome Foundation in their will as a way to help children and adults who suffer from this disorder.

In order to properly thank those of you the Proteus Syndrome Foundation has formed a Sunshine Society to honor and recognize families and friends who have bequeathed to our organization.

Benefits of membership include a formal invitation to the Proteus Syndrome Foundation Family Conference in Washington D.C. at which time you will be introduced to the foremost doctors and researchers in the world concerning Proteus syndrome. You will also meet many families whom your support will benefit. Other opportunities will be given to Sunshine Society members to learn more about Proteus syndrome, the families it affects, and the latest research techniques being used to find a cure for this disorder.

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### Gift Through Your Will

One reason donors make gifts through wills rather than during their lifetimes are to preserve assets for their own use and to maintain current control over the assets in case they want to change a bequest. For many donors, the most significant expression of their life values is made in the form of a charitable bequest in a will. Bequests can be made in the form of a specific gift of cash or property, or a percentage of an estate.

Friends who inform the Proteus Syndrome Foundation of their plan for a bequest to benefit our organization are recognized through the *Sunshine Society*. To confirm your membership in the Sunshine Society, the Proteus Syndrome Foundation will simply request that a copy of the page within your will, naming the Proteus Syndrome Foundation a beneficiary, be submitted to us by your attorney with a cover letter confirming the information. This is to protect you, the donor, and the Proteus Syndrome Foundation, in the event your wishes are contested.

The language of a bequest in a will should be drafted by your legal advisor and can be easily included when drafting a will for the first time, or by adding a Codicil to an existing will. Below are versions of language for an unrestricted bequest that may serve as a useful starting point:

**General Bequest:** used if you intend to make an outright bequest of cash, securities, or other property by designating a specific dollar amount, a particular asset, or a fixed percentage of your estate to the Proteus Syndrome Foundation

I, \_\_\_\_\_ of \_\_\_\_\_ bequeath to the Proteus Syndrome Foundation, a not-for-profit corporation, 8485 Dulwich, Cordova, TN 38016 the sum of \$\_\_\_\_\_ (or a description of a specific asset), for the benefit of the Proteus Syndrome Foundation for its general purposes.

I, \_\_\_\_\_ of \_\_\_\_\_ bequeath to the Proteus Syndrome Foundation., a not-for-profit corporation, 8485 Dulwich, Cordova TN 38016, \_\_\_\_% of my estate for the benefit of the Proteus Syndrome Foundation for its general purposes.

**Residuary Bequest:** ~ • ^ á Á ã ~ Á ^ [ ~ Á ã } c ^ } á Á c [ Á | ^ æ ç ^ Á c @ ^ Á | ^ • ã á ~ ^ Á ] [ estate, after other terms of the will have been satisfied:

I, \_\_\_\_\_ of \_\_\_\_\_ bequeath all the rest, residue, and remainder of my estate (or \_\_\_\_\_ percent of the residue), both real and personal, I give to the Proteus Syndrome Foundation, a not-for-profit corporation, 8485 Dulwich, Cordova, TN 38016 for the benefit of the Proteus Syndrome Foundation for its general purposes.

**Contingency Bequest:** is used if you wish to make a contingency gift, so that the Proteus Syndrome Foundation will receive a portion of your estate if your named beneficiary does not survive you:

I, \_\_\_\_\_ of \_\_\_\_\_ devise and bequeath the

residue of the property, real and personal and whatever situated owned by me at my death, to (name of beneficiary), if (she/he) survives me. If (name of beneficiary) does not survive me, I devise and bequeath my residuary estate to the Proteus Syndrome Foundation, a not-for-profit corporation, 8485 Dulwich, Cordova, TN 38016 for the benefit of the Proteus Syndrome Foundation or its general purposes.

If you are interested in joining the Sunshine Society  
contact the Barbara King at 901-756-9375

Thank you for making a difference.



Matthew Baines



Alex Hoag

## Ways to donate to the PSF

The Proteus Syndrome Foundation relies on the generosity and financial support of donors to ensure that we are able to meet the goals in our Mission Statement.

The Proteus Syndrome Foundation is a not-for-profit organization under IRS tax law and donations are tax deductible to the extent allowed by law.

We gratefully accept many types of donations, as outlined below. For more information on these donation programs contact the PSF Treasurer; Barbara King at 901-756-9375 or [jakebabs@aol.com](mailto:jakebabs@aol.com)

### Gifts of Cash

A gift of cash is the most direct and immediate way to offer support. Please note that as a not-for-profit organization, all gifts are tax deductible to the full extent allowed by law. Gifts can be made in honor or in memory of someone held dear.

OR  
Go to the Proteus Syndrome Foundation web page at [www.proteus-syndrome.org](http://www.proteus-syndrome.org) and click on **Donate** to make a convenient on-line credit card donation .

### Gifts of Stock

A public stock gift can be very tax wise! Appreciated stock held long term (more than one year) can be given to the Proteus Syndrome Foundation, thus allowing you, the donor, to avoid long-term capital gains tax. The full fair market value of the stock is available to the Proteus Syndrome Foundation to support our mission. Not only do you avoid capital gains tax, but you are also entitled to a charitable income tax deduction for the full fair market value!

### Gifts Through Life Insurance

Most people have life insurance coverage to meet the needs that we all can face. But life insurance is often overlooked as a way to make a substantial gift for a relatively modest annual premium.

A donor can name the Proteus Syndrome Foundation as the primary beneficiary of a life insurance policy. The donor t g v c k p u " q y p g t u j k r " q h " v j g " r q n k e { . " y k v j " c e e g u u " v q " v j g r q n k e { " y k n n " d g " k p e n w f However, if the decedent had directed that the Proteus Syndrome c v g Foundation receives the life insurance proceeds, the estate will incur a deduction from the gross estate. A donor can also name the Proteus Syndrome Foundation as a secondary beneficiary to receive the proceeds should the primary beneficiary predecease the owner. A donor may receive more immediate tax benefits for an irrevocable assignment of proceeds or gift of a life insurance policy to the Proteus Syndrome Foundation. Upon the completion of the assignment or gift, the donor is permitted an immediate federal income- v c z " f g f w e v k q p " h q t " v j g -marked u g t value, or the net premiums paid. In order to obtain an income-tax charitable deduction, the donor cannot retain any rights of the policy. If the decedent had directed that the PSF receive the life insurance proceeds

### Matching Gifts

You may double, or even triple your gift to the Proteus Syndrome Foundation by having your employer match your f q p c v k q p 0 " V j q w u c p f u " q h " e q o r c p k g u " q h h g t " v q " o c v e j " v j g completed by the employee. Most companies have guidelines that the non-profit organization and employee must meet d g h q t g " c " f q p c v k q p " e c p " d g " o c v e j g f 0 " [ q w t " e q o r c p { ø u " J w o { q w t " g o r n q { g t ø u " r t q i t c o . " c u " y g n n " c u " v j g " r t q r g t " h q t o u Mail your Matching Gift Form along with your contribution to the Proteus Syndrome Foundation. We will complete and return the form to your employer.

#### Disclaimer:

You should consult your tax advisor regarding how these tax issues may impact your income or estate tax return.

## LEND YOUR SUPPORT

*Proteus Syndrome Foundation, Inc.*

I am interested in supporting Proteus Syndrome Foundation, Inc.

z · Membership \$25 per family annually , (This will be excused if it is a hardship)

z · Professionals \$35 annually,

z · Donation: \$ \_\_\_\_\_

z · Memorial: \$ \_\_\_\_\_ In Honor Of: \_\_\_\_\_

Name: \_\_\_\_\_

Address: \_\_\_\_\_

City: \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_

Phone: ( \_\_\_\_\_ ) \_\_\_\_\_ Country \_\_\_\_\_ Email: \_\_\_\_\_

Family: \_\_\_\_\_ Health Professional \_\_\_\_\_

Friend: \_\_\_\_\_ Self: \_\_\_\_\_

Other: \_\_\_\_\_

Please make check payable ~~Proteus Syndrome Foundation, Inc~~ and mail to 8485 Dulwich, Cordova, Tenn. 38014. ~~Proteus Syndrome Foundation, Inc~~ donations received by PS, Inc. are deductible and go to support services, educate professionals and families, and to fund research to find a cure for those affected by Proteus syndrome.

The Proteus Syndrome Foundation will list our donors on our website from now on in an effort to GO GREEN and help save mailing costs.  
Thank you for understanding.

**Proteus Syndrome Foundation**  
**4915 Dry Stone Dr.**  
**Colorado Springs, Co. 80923**  
**USA**

Non Profit Organization  
US Postage  
PAID  
Colorado Springs CO  
Permit NO. 184

**I**n an effort to improve the quality of life for our family and friends with Proteus syndrome, we welcome ideas from our readers and families on various techniques of management and care, and general and educational suggestions that individuals have investigated and/or found beneficial. This exchange of ideas is welcome. Parents and others have the opportunity to decide if they want to follow through with the suggestions. We do not, however, as an organization, support or endorse any particular treatment, therapy, or medication.

We encourage parents to support one another with suggestions and to contact v j g k t " e j k n f ø u " r j .{ u k e k c p " h q t " h k p