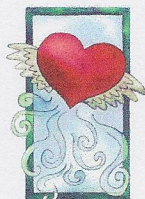


# C.F.S.R. NEWSLETTER

Issue # 40 \* April 2013



## *In Loving Memory*

It is with deep sadness that we begin our first newsletter of 2013 with the loss of two beloved members of our family, due to complications from SPMD. Our dear cousin, Donald (Donny) Swantek and loving sister Norma Chillemi, both 69, leave us with beautiful memories and love in our hearts.

Donny passed away, Friday, January 18th, in Rahway Hospital. He had lived a full life despite his disability, helping others through his music and ministry. He loved people and brought "light" to everyone who talked to him. His voice brought healing to others and his service to his community will be truly valued always.

Norma passed away, Monday, February 4th, in Riverview Medical Center, Red Bank, N.J., peacefully surrounded by her family, daughter, Vicki Cicala, son-in-law Frank, grandchildren, Danielle and Frankie Jr., Companion Howard "Scotty" Scott, Sisters, Fran Comar, Carol Castagna, Denise Lance, Susan, Angela & Pam Chillemi, Patty & Ralph Colasurdo. Brothers, Bill & Gary Chillemi. Nieces, Jill Kane & Brooke Pittman.

She was a loving and caring person, a wonderful mother, grandmother, great-grandmother, sister, aunt and friend.

Her support and loving, open heart touched so many lives. Family was very important to her and she always had a helping attitude towards everyone. Norma managed to live with great pride and a healthy outlook. Her heroic spirit still prevailed despite the difficult challenge of losing her son, Paulie, in 2005, also from SPMD. Her presence will be deeply missed by all who knew her!

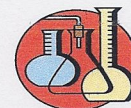
It was at the request of her family, in lieu of flowers donations be made to CFSR. Deep appreciation is extended to all who came out to bid farewell to Norma and showed their support to our family.

We receive so many lovely cards and generous donations in memory of our beloved Norma. A total of \$2,720.00 has been received thus far. Norma would have been deeply moved by this demonstration of support and love.

We gratefully acknowledge the following donors:

Assistive Choices Inc.  
Oswaldo & Maria Andreade  
Michael & Christina Bonafide  
Nancy Bove

Edward & Susan Carroll Ferguson - Lakewood Branch  
Frank & Carmella Chillemi  
Ronald Delfilipo  
Susan Dickman  
E.L.C. Staff  
Angelina Gruner  
Emily & Dennis Kopin  
Donna Levy  
Leslie McEwan  
Donna & Jeffrey Merceron  
Craig & Patty Mitchell  
Lewis & Joanna Scott Picher  
John & Carol Poll  
Richard Sistad Sr.  
Raymond & Frances Scott  
Dorothy & Johnathan Scott  
Candance Tice Tomasik  
Gloria Zapin  
33 West Salon Staff



## RESEARCH UPDATE

Reported by Dr. Hirano of Columbia University :

Briefly, we have studied the male FHL1 mutant until ages 20-24 months (mice typically live about 24 months) and we are still analyzing female mutants. We expect to see more dramatic changes in the male mutants because the disease is X-linked. We assessed survival, weight, maximum muscle strength, spontaneous activity, and exercise capacity at age 3-5 months (young mice), one year (adult mice), and older than 1 year-old (old mice).

## RESEARCH UPDATE ( Cont'd)

We observed that affected females and males have normal life spans.

At about age 7-10 months, the mutant males weigh less than normal. We have not observed any differences in female mutants compared to normal females. In addition, 7-10 month old males showed decreased forelimb ("arm") strength and reduced exercise capacity.

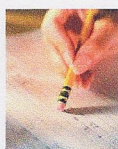
Plasma creatine kinase was normal in all mice. In male mice over age 1, muscle shows mild signs of degeneration by microscopic analyses.

We studied cardiac function in the mice at different ages, but we did not observe significant differences between affected and unaffected animals.

We assessed the FHL1 protein, and the morphology of several muscles involved and not involved in the disease, in affected males. Interestingly, FHL1 levels are comparable in affected and unaffected animals in 3-5 months, partially reduced in some muscles of 10 months old affected animals and completely absent in all the muscles of the 2 years old animals.

In summary, as expected, affected male mice have earlier onset and more severe manifestations of the disease, compared with females. Clinically, male mutant animals show an adult onset mild myopathy while female mutants may have late-onset disease.

Our foundation is encouraged by these findings and are currently in the process of issuing another grant to fund continued research. We will keep you updated as findings become available. Look for details in our next newsletter.



### ANNUAL FINANCIAL REPORT

The following is a financial summary of 2012

<b><u>INCOME :</u></b>	
Donations:	1045.00
Fundraiser :	
Bracelets	32.00
Holiday Prize Raffle	3490.00
Interest Earned	<u>764.41</u>
<b>TOTAL :</b>	<b>5,331.41</b>
<b><u>EXPENSES</u></b>	
Account Analysis Charge	805.68
Ocean First Bank	500.00
Insurance	1,079.63
IRS Fee	31.00
Licenses & Permits	380.00
Pay Pal Fee	8.98
Printing & Reproduction	82.33
Prize Raffle Purchase	628.99
State Fee	60.00
Website Develop/Maint.	<u>350.00</u>
<b>TOTAL</b>	<b>3,895.61</b>
<b>Total net income</b>	<b>\$1435.80</b>

### *Fundraising Efforts:* ( first quarter of 2013)

<b><u>General Donations</u></b>	
Deborah & Wayne Smith	10.00
William & Mary Albers	15.00
Stan & Muriel Haber	18.00

## Fundraiser Follow-up:

### *Holiday Prize Raffle*



Our 2012 Fall Fundraiser was a great success! We raffled off the new Apple IPAD3 and

IPOD Touch around the holidays. The winning tickets were picked at Mulberry Street Italian Food Center in Brick, NJ .

The Grand prize winner of the IPAD3 was Charlie from Brick, NJ . The winner of the IPOD Touch was Frank, from Toms River, NJ . This event brought in a net total of 2,400.00!

We like to take this time to acknowledge all the people who help sell the raffle tickets :

Carol Castagna  
Kathrine Cauley  
Dave Cameron  
Angela Chillemi  
Bill Chillemi  
Pamela Chillemi  
Susan Chillemi  
Patty & Ralph Colasurdo  
Mike Colonna  
Haya Gray  
Jill Kane  
Debbie Kay  
Denise Lance  
Jerry Lance  
Maryellen Tutzauer  
Kathleen Theivon  
Patty Varga

We are truly grateful for their continued support!





**"With A Little Help from Our Friends"**

**Love. Hope. Family.**

Students from Centenary College of New Jersey, led by Kelley Carvalho, have created our Love, Hope, Family Campaign fundraiser on-line with great success!

Kelley is a friend of our family, who was assigned, along with her Sales & Sales Management classmates, to create a fundraiser on-line as part of their spring semester final project. We are delighted that Kelley and her class chose to raise awareness and funding for C.F.S.R.!

Kudos to Kelley and her classmates for thinking of us!

Their class has campaigned for C.F.S.R. on the website [www.indiegogo.com](http://www.indiegogo.com) and will continue until May 1st. Their goal is to raise \$3,000.00!

If you like to view their video and help support them achieve their goal, go to the website by typing:

<http://www.indiegogo.com/projects/love-hope-family>



We are forever grateful for their efforts and helping hands in our search to find the cure for SPMD!



**Visit our Website !**

[www.CFSR.Org](http://www.CFSR.Org)

We been receiving lots of donations through our website. Be sure to check it out!

**Make sure your ...  
YOU'RE ON THE  
List...**

If you know someone who would like to receive our newsletter please have them send us their information by going to our website.

Select the drop down box:  
- Join our mailing list.



**LIKE us on facebook**



**Bracelets**

**LOVE.HOPE.FAMILY.**

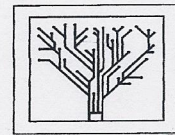
They are still available to purchase for \$1.00 each at our fundraisers and throughout the year. If anyone is interested in buying one or selling them please call: (732) 914-1858.

**Fundraiser Update:**

We are hoping to arrange some fundraisers in the fall or for next year. We have some potential ideas that are circulating. If anyone is interested in chairing, volunteering, for a fundraiser or have any ideas about one, please contact us at (732) 914-1858.



Any financial contributions may be sent to :



C.F.S.R. Foundation, Inc.  
112 Mapletree Road  
Toms River, NJ 08753

For online donations visit  
[www.cfsr.org](http://www.cfsr.org)



Thanks again, as you help us continue on this path to successfully heal all those affected with SPMD. We look forward to the celebration of finding the cure and returning back to wellness and health!

