

# C.F.S.R. NEWSLETTER

Issue # 41 \* April 2014



## *In Loving Memory*

2013 was an emotional and challenging year for us, having lost several CFSR members.

Our dear and loving sister, Susan Chillemi, 61, passed peacefully on Sunday, December 8th, surrounded by her loved ones, from complications of SPMD.

Susan is remembered for her loving kindness, compassionate heart and generous spirit. She lived her life graciously while always maintaining her strong independence. She was so grateful and appreciated all the loved ones in her life. She will be deeply missed by all who knew her, as she touched so many with her thoughtful and caring ways.

A dear friend, caretaker and CFSR supporter, Delton (Del) D. Amor, 50, passed away on December 31st, while in Ocean Medical Center of Brick. He is fondly remembered for his willingness to lend a helping hand to those relatives and friends in need.

In 2014, we lost another loving family member, Paul Puccerella Sr., 70, passed away peacefully at home on Monday, February 17th. He was a great supporter and worked very hard for our foundation. His kind soul will be

deeply missed by all his family and friends.

It was at the request of all their families, in lieu of flowers donations be made to CFSR. Deep appreciation is extended to all who came out to bid farewell to Susan, Delton and Paul and showed their love and support to our family & friend.

We received so many lovely cards and generous donations in their memory. A total of \$4,080.00 has been received thus far. They would have been deeply moved by this demonstration of support and love.

We gratefully acknowledge the following donors:

- Assistive Choices Inc.
- S & R Amor
- Oswaldo & Maria De Andrade
- Bank of America - West Dover
- Michael & Christina Bonafide
- Bob & Julie Burczyk
- Edward & Susan Carroll
- Frank & Carmella Chillemi
- Jessica Chillemi -Stevens
- Early Learning Center Staff
- Joseph & Grace Fedorcsak
- Joanne Fotis
- Karen Lane
- Donna Levy
- Mary & John Lepping
- Ruth Matilsky
- Leslie McEwan
- Rebecca McGill
- Thomas & Elaine McGlynn
- Donna & Jeffrey Merceron
- Craig & Patty Mitchell
- William & Joann Miller

- Mary Neumann
- Charles & Mary Newman
- Adrienne Rowe-Violet Petals
- Yoga Oasis
- Nena & Thomas Ottmer
- Aleta Rankin
- Elaine & Mark Sugarman & Family
- Debra & Samir Sofer
- David Stein & Family
- Julie Stein-Buechelman & Family
- Amy Stein-Schluskel & Family
- Linda Sullivan-Hill
- Mary Taft
- Maryellen & Gene Tutzauer & Family
- Douglas & Jennifer Weimer
- June & Nick Zagar
- Gloria Zapin
- Maria Zito-Kaufman



## RESEARCH UPDATE

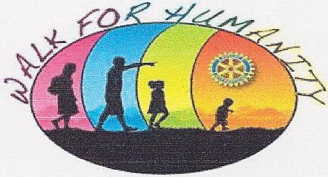
Last year we reported our intention of further funding the research of SPMD. In June, 2013 CFSR issued a \$25,000 gift to the FHL1 Mouse Study headed by Dr. Michio Hirano with Columbia Presbyterian Medical Center. He has since reported that FHL1 mutant males showed mild weakness and mild signs of myopathy. He also presented the study at the World Muscle Society meeting last fall, explaining the results so far. He will be writing a paper describing the research on the mice later this year.



## Fundraisers :

We start off this year with a community fundraiser.

### 5K Walk for Humanity



Sponsored by Brick Rotary Club

## Support Team C.F.S.R.

Saturday, April 5th, 2014

Drum Point Sports Complex, 41  
Drum Point Road, Brick, NJ

Several CFSR members have created a team and are walking in this fundraiser. We are dedicating this walk to our loved ones who are afflicted with this disease as well as the ones that have passed away . Please show your support to the foundation by walking with our team and collecting donations or by donating a pledge to our team!

Donations need to be received by April 1st, made out to :

“Brick Rotary Charitable Foundation”,

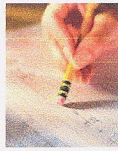
mailed to :

112 Mapletree Rd.  
Toms River, NJ 08753

For more information and to download forms on this event, please visit the website:

[www.brickrotary.com](http://www.brickrotary.com)

Come out and join in on the fun!



## ANNUAL FINANCIAL REPORT

The following is a financial summary of 2013

### INCOME :

Donations:	6428.00
Fundraiser s:	
Bracelets	90.00
Love Hope Family	1089.00
Bank Correction -	500.00
Interest Earned	<u>458.97</u>

TOTAL : 8,565.97

### EXPENSES

Account Analysis Charge	928.96
Medical Research	25,000.00
Indiegogo.com fee	79.62
Insurance	1,079.63
Licenses & Permits	200.00
Office Supplies	175.05
Pay Pal Fee	57.22
Postage & Delivery	200.00
Printing & Reproduction	507.76
Return Check not deposited	5.00
State Fee	60.00
Website Develop/Maint.	<u>350.00</u>
TOTAL	<u>28,643.14</u>

Total net income \$-20,077.17

### *Fundraising Efforts: ( first quarter of 2014)*

#### General Donations

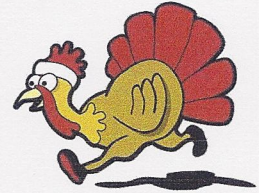
Deborah & Wayne Smith	10.00
William & Mary Albers	15.00
Kennth & Sandra Shapiro	50.00



Working together with MDA

## RAISING AWARENESS

### 3rd Husky Turkey Trot Fun Run For Muscular Dystrophy



Gloria English , Health Care Service Coordinator, NJ Chapter of MDA , asked Pamela Chillemi (CFSR ) to be a representative for MDA on November 20, 2013. The children of Hooper Ave Elementary School competed in their 3rd Turkey Trot Fun Run, raising money for Muscular Dystrophy Association. Several members of the CFSR Foundation , Pamela Chillemi , Angela Chillemi & Patricia Colasurdo, cheered the young turkey trotters on as they ran 1/2 mile and competed for participation ribbons. The first place winner, boy and girl of each grade level won turkeys for their families. The kids were adorable running around the track while sporting turkey hats!

We received an email from the teacher who ran this event, Kim Rinkerman, thanking us for being there to support the children.

We look forward to possibly working with them again next year!

## Love. Hope. Family



### Fundraiser Follow-up

In the spring of 2013, as a semester project, Kelley Carvalho and her classmates at Centenary College of NJ created a fundraiser called LOVE, HOPE, FAMILY. Using their own video on Indiegogo.com, they collected donations and helped raise awareness on SPMD. They raised for CFSR a total of \$1,089.00! Our heartfelt appreciation goes to everyone involved and all the donors and their caring, loving support for funding research to help all people living with SPMD.

THANK YOU! ♥♥♥



*We get by with a little help from our friends...*



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

<https://www.facebook.com/pages/CFSR-Foundation-Inc/198198900218449>



Bracelets

LOVE. HOPE. FAMILY

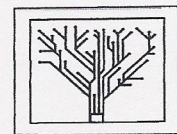
They are still available to purchase for \$1.00 each at our fundraisers and throughout the year. If anyone is interested in buying one or selling them please call: (732) 914-1858.

## Fundraiser Update:

We are hoping to arrange some fundraisers in the fall . 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!