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Susan Gouveia

From: Lashway, Lisa
Sent: Thursday, April 24, 2014 10:34 AM
To: Canning, Sean; Susan Gouveia
Subject: FW: Supporting FOP Awareness
Attachments: Fibrodysplasia Ossificans Progressiva.rtf; Fibrodysplasia Ossificans Progressiva.docx

Lisa Lashway
Mt. Olive Twp. Clerk
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PO Box 450
Budd Lake, NJ 07828

From: MCANJ IT Committee [mailto:WebsiteAdmin@njclerks.org]
Sent: Thursday, April 24, 2014 10:21 AM
To: members@njclerks.org
Subject: Supporting FOP Awareness

On behalf of Lorraine Kubacz, Wall Township Clerk, please have your municipality consider supporting by proclamation Fibrodysplasia Ossificans Progressiva (FOP) awareness. Attached is the Wall Township Proclamation presented last night. The below email explains what the disorder is about and where to send the Proclamation. Some municipalities have already done this as you can see below, but they are trying to get all 566 municipalities on board.

Thank you for your support.

To: The Honorable Clinton C. Hoffman
Mayor / Wall Township - Monmouth County

Good Morning Mayor Hoffman

My name is Gary W. Whyte and I reside in Mountainside, New Jersey with my wife and three { 3 } sons. A few years ago I learned that my friends daughter was diagnosed with Fibrodysplasia Ossificans Progressiva { F.O.P. } when she was nine { 9 } years old. My sons and I started an ' Awareness Campaign ' to let our Elected Officials know about F.O.P. and I have just concluded my 13th Annual Comedy Show Fund-Raiser for F.O.P. in which the money raised goes directly towards the purchase of research equipment for the F.O.P. Lab located at the University of Pennsylvania. Michelle Charlesworth from Channel 7 Eyewitness News attended our 3-29-2014 fund-raiser and spoke about it on her 9:00 Sunday morning news broadcast on 3-30-2014.

About F.O.P. in brief: If a child were to receive trauma to a muscle, tendon and/or ligament, it wouldn't heal like it would in you and I but instead turns to ' BONE ' and then the bone moves throughout the body and essentially the child develops a ' Second Skeleton ' within the confines of their normal skeleton. After 15 years of hard research, in April of 2006 they announced that they found the ' Gene ' responsible for causing F.O.P. and have been aggressively working on trying to find a cure and/or treatment.

The ' Awareness Campaign ' that my sons and I started essentially asked all 566 New Jersey Mayors to consider adopting a Proclamation and/or Resolution on behalf of F.O.P. and as of this date and time we've received a total of 327 Proclamations / Resolutions to-date. It is our goal to hopefully one day display this Proclamation / Resolution Book in Washington D.C. and hope that it will depict a Proclamation / Resolution from all 566 New Jersey Mayor's, on behalf of and in support of the more-or-less twelve { 12 } children / young adults that are afflicted with F.O.P. in the State of New Jersey and equally show our concern for all other children afflicted with F.O.P.

All 21 County Freeholder Board's have issued either a Proclamation or Resolution in support of FOP Research and Awareness !

I've taken the liberty of up-dating the below list. We now have a total of 327 Proclamations / Resolutions from Mayor's across the State of New Jersey and are requesting your support as one of the 239 municipalities that we have not heard from yet.

There is a ' Sample Proclamation ' in the attached file below but it's sort of out-dated. Let me know if you need anything further from my side besides what I've presented already and ' THANK YOU ' for your consideration and assistance in this regard.

Thanks again and look forward to hearing from you. For further contact you can do so via email or call my office at 973-712-4216. Thank You

Best Regards Gary

Proclamation / Resolution should be mailed to:

Mr. Gary W. Whyte

289 Old Tote Road

Mountainside, New Jersey 07092-1835

Here is a summary as to the number of municipalities in each county that have we have not heard from as of this date and time. The following for your guidance and information:

Atlantic County	=	07
Bergen County	=	21
Burlington County	=	22
Camden County	=	21
Cape May County	=	03
Cumberland County	=	09
Essex County	=	03
Gloucester County	=	16
Hudson County	=	01
Hunterdon County	=	17

Mercer County = 07

Middlesex County = 06

Monmouth County = 25

Morris County = 20

Ocean County = 12

Passaic County = 04

Salem County = 10

Somerset County = 09

Sussex County = 12

Union County = 100% Support

Warren County = 14

Please Help Us Narrow Down This Number = 239

Thanks again for all your help. Best Regards.

**RAISING AWARENESS OF
FIBRODYSPLASIA OSSIFICANS PROGRESSIVA**

WHEREAS, Fibrodysplasia Ossificans Progessiva is an illness characterized by normal bone forming in muscles and connective tissue, forming an extra skeleton that immobilizes the body; and

WHEREAS, Fibrodysplasia Ossificans Progressiva affects children, usually in the first or second decade of life being diagnosed by the age of ten, depriving them of normal development; and

WHEREAS, i t is estimated that 2,500 people worldwide are afflicted with Fibrodysplasia Ossificans Progressiva, with 200 diagnosed cases in the United States and 12 cases in New Jersey; and

WHEREAS, currently the University of Pennsylvania is the only medical research facility investigating a cure for Fibrodysplasia Ossificans Progressiva; and

WHEREAS, numerous states, countries and international organizations have joined together to increase public awareness of this devastating, rare genetic disorder, to promote research to find the cure; and

WHEREAS, the Township Committee of the Township of Wall wishes to help to increase awareness of Fibrodysplasia Ossificans Progressiva and to provide public support to find a cause and a cure for this devastating disorder.

NOW, THEREFORE, I, Clint Hoffman, Mayor of the Township of Wall, on behalf of my colleagues on the Township Committee, wish to raise awareness of this devastating disease and support research to find a cause and cure for **Fibrodysplasia Ossificans Progessiva**. We urge all residents of Wall Township to learn about this devastating disorder with the hope of developing a treatment and cure.

April 23, 2014

**RAISING AWARENESS OF
FIBRODYSPLASIA OSSIFICANS PROGRESSIVA**

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April 23, 2014