

DAWS WEEKLY

VOLUME 1, EDITION 2



Quick Hits for the week of June 12th through June 18th 2017:

- Back on December 29th 2016, the FDA approved a drug called Spinraza (created by Biogen). This appears to be a breakthrough in treating SMA.
- Cure SMA, the largest SMA charity within the United States, will hold its annual North Jersey Chapter Walk-n-Roll on June 25th, in North Brunswick Community park at 9:30am.
- Cure SMA is also scheduled to hold its Annual Conference from June 29th through July 2nd 2017 in the Contemporary Hotel at Walt Disney World in Orlando, Florida. DAWS will have representation at the conference, and it provides a great forum to maintain our understanding of the current state of affairs with regard to SMA research and family needs.

SMA FACT:

SMA AFFECTS APPROXIMATELY 1 IN 10,000 BABIES.

- There are a number of SMA charities within the United States, each with their own specific history and mission. Several of these charities have joined together to form the Spinal Muscular Atrophy Coalition.
- SMA charities are also located in the United Kingdom (The SMA Trust funds over 75% of the charity-funded research in SMA within the UK), as well as other countries all over Europe. Several of these SMA-focused charities are members of SMA Europe. They range all across the continent, and include Asociația SMACARE (Italy), Fundacja SMA Poland, Fund AME (Spain), SMA Schweiz (Switzerland), FSMA Iceland, and Children with SMA (Ukraine).
- SMA charities stretch all the way to Australia (Families of Spinal Muscular Atrophy), further illustrating the ongoing global need to continue to push forward with regard to research and family assistance for those affected by this genetic disorder.

A Tip of the Cap.....

DAWS would like to express our sincere thanks to those who donated to our runners over the past week as part of the 2017 Marine Corps Marathon:

- Kim and Matt Johnson
- Tracey Pearson
- Stacey and Stefan Kelsall
- Anne Shear
- Kim Scharoff
- Team Grace

THANK YOU ALL SO VERY MUCH FOR YOUR SUPPORT!!!!!!!!!!!!

RUN WITH DAWS....AND THE MARINES!



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Do Away With SMA ("DAWS") is EXTREMELY PROUD and HONORED to announce that we have been named an OFFICIAL CHARITY PARTNER of the 2017 Marine Corps Marathon!!!! There are only 40 spots available for this incredible marathon journey...and we are sure that runners will snatch these entries up FAST!!!!

Here's what our runners get by joining our cause and running with DAWS:

- A training plan to help you go from casual runner to mission ready
- A team technical shirt as well as various other awesome team swag
- Access to our coaches through email, bi-weekly skype call, and group conversations within our closed Facebook group to support you during this incredible journey
- Tips and tricks to get you prepared for race day, including group conference calls on nutrition, race gear, and handling the mental aspect of 26.2 miles
- A race weekend carbo-loading pasta-filled team dinner
- ...and LOTS, LOTS MORE!!!!!!

In order to join our merry band of marathon-crushing runners, we ask each athlete to help us fund raise a minimum of \$750 by August 15th 2017. For more information, check out our website (www.doawaywithsma.org) or drop us a line at info@doawaywithsma.org.

HERE'S HOW YOU CAN FOLLOW ALL OF THE ACTION.....

DO AWAY WITH SMA

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NEW YORK, NY 10023

(347) 952-9023

FACEBOOK: DO AWAY WITH SMA

INSTAGRAM: DAWSMA

TWITTER: @DAWSFORSMA

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WWW.DOAWAYWITHSMA.ORG