

# 2014 YEAR IN REVIEW



January 2015

**The Patrick Ring Foundation (TPRF)** is a non-profit organization dedicated to spreading awareness of Epilepsy & SUDEP (Sudden Unexpected Death in Epilepsy). The funds raised will help The Patrick Ring Foundation in achieving our goal of supporting Epilepsy Service Dog Programs, supporting organizations that provide assistance to people with Epilepsy and getting Epilepsy and SUDEP the attention they deserve.

TPRF was established in early March 2014 after Patrick passed away from SUDEP on February 6, 2014. (Please visit our website to read Pat's story.) Patrick was enrolled in the North American SUDEP Registry at NYU shortly after his passing. This registry helps researchers learn more about SUDEP –its causes, and possible means of reducing risks.

Prior to the establishment of the foundation, donations were made in Patrick's name to the Epilepsy Foundation. These donations totaled more than \$12,000!

On **March 22nd**, a team of our supporters attended the **National Walk for Epilepsy in Washington, DC**. They carried purple flags in remembrance of Patrick, provided by the **SUDEP Institute**.



## Purple Day

"Purple Day is an international grassroots effort dedicated to increasing awareness about epilepsy worldwide. On **March 26th** annually, people in countries around the world are invited to wear purple and host events in support of epilepsy awareness."

(Source: <http://www.purpleday.org/>)

Hundreds of our supporters wore purple on this day in 2014 and sent in pictures of themselves, their coworkers, their children and even their family pets sporting purple! Pictures were tagged **#purpleforpat**



One of the many offices who participated in Purple Day in support of Pat.

TPRF announced its **"Wrap Your Head Around Epilepsy"**™ Campaign on **March 29th**. The symbolic visual of wearing a purple bandana is to bring attention to Epilepsy.

## Paint the Pony Purple

On **March 30th**, a huge group of Patrick Ring Foundation supporters attended the Epilepsy Foundation of NJ's Paint the Pony event at the Stone Pony in Asbury Park, NJ. Patrick's fiancé was a guest speaker at the event, telling Patrick's story and bringing awareness to SUDEP.

### The Truth About Epilepsy:

- **1 in 26 people** will be diagnosed with Epilepsy in their lifetime.
- 3 million Americans and 65 million people worldwide currently live with epilepsy.
- **Epilepsy affects more people than multiple sclerosis, cerebral palsy, muscular dystrophy and Parkinson's combined.**
- It is estimated that up to 50,000 deaths occur annually in the U.S. from prolonged seizures, Sudden Unexpected Death in Epilepsy (SUDEP), and other seizure-related incidents such as drowning and other accidents.
- SUDEP accounts for 34% of all sudden deaths in children.
- **SUDEP is now recognized as the leading cause of mortality associated with epilepsy.**

(Source: Epilepsy Foundation)



Tara Lange, Pat's Fiancé

## Pawn Stars Donation

Rick Harrison, of Pawn Stars Fame, suffered from childhood epilepsy and has supported various foundations in their goals of spreading epilepsy awareness. TPRF Board Member Becky Bennett contacted Mr. Harrison and, after hearing Pat's story, he was eager to show his support of our efforts.

Mr. Harrison presented Becky with a very generous donation and a VIP Vacation Package to Las Vegas for us to auction off as a fundraiser.



Rick Harrison & Becky Bennett

## Kathy Ward Memorial Fund Donation

TPRF was a proud beneficiary of the 13th Annual Kathy Ward Memorial Fund Blue Claws Night in Lakewood NJ. Thank you to the Ward Family for your generous donation!

## Golf Outing

TPRF's 1st Annual Golf Outing was held on August 11th at Eagle Oaks Golf & Country Club in conjunction with Woody's Roadside in Farmingdale, NJ.

The event was a huge success with a full field of golfers and many non-golfers who participated in the after party at Woody's, which included a silent auction, 50/50, raffle



## 2nd Annual Epilepsy Awareness Day at Citi Field

TPRF submitted our group photo from The National Epilepsy Walk to The Epilepsy Foundation of Metropolitan New York as part of a contest in hopes it would be shared at the 2nd Annual Epilepsy Awareness Day at Citi Field. We won tickets to the game and attended the event on June 11th.

## PAME

Two of TPRF Board members attended the PAME (Partners Against Mortality in Epilepsy) Conference June 19-22 in Minneapolis, MN. This four day evening event was the 2nd PAME conference devoted predominantly to SUDEP.

What makes this conference so valuable is having clinical (physicians, neurologists), basic science (researchers) and patient/family attendees all come together at the same time—It has been critical for the researchers and doctors to see the impact SUDEP has left on so many people. Our attendees met many individuals who have lost their loved ones, particularly their children, and have developed lasting relationships with them as a result. As we have learned, the grief from losing a loved one to SUDEP is unique and to meet others who immediately know exactly what you are going through is priceless.



Patrick's mother, Susan Ring

One of the presentations showed the significant health burden of Epilepsy—101,000 years of life are lost due to SUDEP (2nd only behind stroke in neurological disorders).

SUDEP may be caused by changes in breathing, heart rhythm, brain activity, or a combination of these factors.

SUDEP may also be related to the sleep and arousal systems (apnea, serotonin, etc.) Nocturnal seizures are thought to increase the risk of SUDEP.

A component of Epilepsy that we were not aware of was the direct link with depression, and in some cases, suicide. We also learned that using anti-epileptic drugs is not a risk factor for SUDEP, but non-adherence is.

TPRF is invested in ensuring that another PAME conference is held in 2016 as it is so important to continue having those personally affected by SUDEP to come together and hear first hand what critical research is being done to prevent SUDEP in the future.

## Pumpkins For a Cause

TPRF volunteers pre-painted more than 70 purple pumpkins in preparation for the sale and event! On October 11th, we hosted a pumpkin decorating party at Kim's White Tiger in Burlington, NC. Thank you to Club Express for helping to sponsor this event! There was entertainment for the kids provided by Gambol the Clown and everyone had a great time showing their support of Epilepsy & SUDEP.



## 1st Annual March on Epilepsy

Despite the cold and rainy (ok, miserable!) conditions, hundreds of people participated in our 1st Annual March on Epilepsy on November 1st at Bucks Mill Recreation Area in Colts Neck, NJ. We also had an amazing group of volunteers and sponsors who helped make this such a successful event!

Trophies were awarded to the winners in each category and all children received medals. For those who were unable to make the event, there was an option to sign themselves or their pets up as virtual walkers to show support of service dogs — a portion of the funds were raised specifically to support a family with their service dog handler fees.



## 1st Annual Epilepsy Awareness Gala

On November 7th, supporters in NC got dressed up and attended our gala at the Mackintosh on the Lake clubhouse in Burlington, NC. The event featured a silent auction, tricky tray raffle, 50/50, food, drinks and music. Funds and awareness were raised while everyone had a really fun night out!



## News & Media

- Sep 20th: The Times News (Burlington, NC) featured Pat's story and the Pumpkins for a Cause Event.
- Oct 29th: 94.3 The Point, a NJ radio station, featured Pat's story on one of their morning show blogs.
- Nov 7th: Fox 8 News in NC featured Pat's story with an interview with Pat's sister and parents.
- Nov 28th: TPRF turned Black Friday into Purple Friday. This day was supposed to be Patrick's wedding day—his fiancé created a beautiful video tribute in honor of him. Please visit our website and take a moment to watch this wonderful video and share it to help spread the awareness further.



Please visit our website to see all photos, videos and press coverage [www.patrickringfoundation.org](http://www.patrickringfoundation.org)

## TPRF Gives Back

The Patrick Ring Foundation donated more than \$16,000 in 2014!

\$6000 was provided through a grant to help the Frost Family with their monthly service dog handler fees. This grant enables Epic to be with Mia at school each day to keep her company and to help keep her safe. This family is very active in the Epilepsy community and TPRF is proud to support them.



TPRF donated \$10,500 combined to these 3 organizations whose work is in line with our mission.

## 2015 Events

Stay tuned for details on these upcoming events:

- Purple Day—Thursday, March 26th—International Event
- 2nd Annual Golf Outing—Forsgate Country Club—NJ
- 2nd Annual March on Epilepsy—Colts Neck, NJ—Fall
- 2nd Annual Epilepsy Awareness Gala—Burlington, NC—Fall

For more information about the foundation, how you can help get involved with our cause, or to make a tax-deductible donation, please visit us on the web at: [www.patrickringfoundation.org](http://www.patrickringfoundation.org)

You can also visit our Facebook page for regular updates at: <https://www.facebook.com/ThePatrickRingFoundation>