

NERVEember® 2016 Official Partners & Participating Support Groups Information Packet



This information pack including official logo, sample posts and banner, will help you raise awareness and organize your own communication around the month of November with the iPain's NERVEember project.

Please use it as a guide and if you have any questions, do get in touch: barby@internationalpain.org or rachel@internationalpain.org

Don't forget to share with us the details of your awareness campaign, as well as plans, media coverage and photos from your NERVEember events. Send them to: ken@internationalpain.org to get onto the official calendar.

What is NERVEember?

NERVEember takes place every year for the full month of November.

NERVEember® brings awareness to the 150 plus conditions that have nerve pain as a symptom. The International Pain Foundation hosts the OFFICIAL NERVEember events every year. Since its inception, tens of thousands of nerve pain patients and organizations have signed on to help promote NERVEember.

The main objective of NERVEember is to **raise awareness** about the **nerve pain diseases and the impact it has on the patients' lives**.

The campaigns primary target is the general public and it also seeks to raise awareness among policy makers, public authorities, industry representatives, researchers, health professionals and anyone who has a genuine interest in nerve pain diseases.

Since the first NERVEember was launched by IPAIN in 2009, thousands of events have taken place throughout the world. The campaign has reached millions of people and has resulted in a great deal of media coverage. Did you know the color orange is the international color for chronic pain awareness? In the over 150 conditions that do have nerve pain; RSD is one of the most painful conditions. Yet this condition is often misunderstood, mistreated and misdiagnosed. #NERVEember is International Nerve Pain Awareness Month which includes conditions such as RSD, CRPS, Diabetes, and many more. During the month of NERVEember the iPain Foundation (@powerofpain) will present an awareness task every day that we can all perform!

The political momentum that has resulted from NERVEember also serves advocacy purposes. It has notably contributed to the advancement of access to care issues in the United States and Australia.

This project has progressively become a worldwide awareness effort with participation in over 16 countries around the world in 2015. Thousands continue to take part in the project and we hope many more will join in 2016. There are some support groups that have decided to raise nerve pain disease awareness further, for example, patients in Australia declared November 2, 2015 *Colour the World Orange Day*. Then there is Danielle Cosgrove from Trinidad who is the creator of The Project 3x5 and started the *#OrangeInitiative which is year round*. Anyone can bring awareness to conditions like #RSD #CRPS and #Diabetes simply by posting every day in #NERVEember and with @powerofpain as we #PAINtTheWorldOrange #ColourTheWorldOrange #MakeTheWorldOrange.

During NERVEember you can find information about all the events happening around the world that are working on building awareness for people living with nerve pain and their families. If you are planning an event, register your event details by emailing them to ken@internationalpain.org to get your event listed on the site.

NERVEember® 2016 Official Partners & Participating Support Groups



History of NERVEember

NERVEember is officially used to represent Neuropathy Awareness Month, RSD, Reflex Sympathetic Dystrophy, CRPS, Complex Regional Pain Syndrome, and Diabetes Awareness Month (November) by the Power of Pain Foundation. The word NERVEember(R) for this purpose was created by Barby Ingle in Oct. 2009. These awareness activities all started back in 2007 by the Power of Pain Foundation, a 501(c)(3) nonprofit. As the neuropathy community and nerve pain awareness movement grew, the awareness activities increased and grew into Nerve Pain Awareness Month or now referred to in the pain community – NERVEember.

NERVEember(R) brings awareness to the 150 plus conditions that have nerve pain as a symptom. The International Pain Foundation hosts the official NERVEember project events every year. Since its inception, tens of thousands of nerve pain patients and organizations have signed on to help promote NERVEember.

During the month of November, many people throughout the world come together for the nerve pain community. Events are held. Articles are written. Facebook statuses are updated. Instagram photos are posted. Videos are created and spread online. Proclamations are issued. It is important to remember, that these are all things that can happen throughout the entire year, not just in November.

Target Audience

NERVEember was started by iPain (formerly *Power of Pain Foundation*) and is patient-led. Therefore, the primary drivers and beneficiaries of the international campaign are people living with a nerve pain disease and their families.

Our main target audiences are the following:

- Health professionals and caregivers
- Local businesses that serve the pain community
- Pharmaceutical, durable medical equipment companies and biotech industry
- Politicians, policy-makers and public authorities
- Researchers, clinicians and academics
- The general public and the media
- We encourage everyone who has an interest in nerve pain diseases to join the movement as long as they respect the spirit of NERVEember.

NERVEember 2016 Theme & Slogan

Theme: *iPainPOP*

Slogan: *Do You Have the Nerve to Be Heard; Join the virtual choir*

2016 marks eight consecutive, successful years of NERVEember. Continuing the momentum, NERVEember 2016 focuses on making sure that the voices of those living with a nerve pain disease are heard.

Over 150 different nerve pain diseases have been identified to date, directly affecting the daily life of more than 700 million people worldwide. November 2016, people living with or affected by a nerve pain disease, patient organizations, politicians, medical professionals, researchers and industry will come together in solidarity to raise awareness of nerve pain diseases.

The NERVEember 2016 theme 'iPainPOP' recognizes the crucial role that patients play in voicing their needs and in promoting change that improves their lives and the lives of their families and caregivers.

NERVEember® 2016 Official Partners & Participating Support Groups



The NERVEember 2016 slogan is 'Do You Have the Nerve to Be Heard. Join the virtual choir' and appeal to a wider audience such as those that are not living with or directly affected by nerve pain diseases to help the nerve pain disease community in making known the real impact of nerve pain. People living with a nerve pain disease and their families are often isolated. Better societal supports can help to bring them out of this isolation.

NERVEember was created by a pain patient, is patient-led and is coordinated annually by iPAIN. The primary drivers and beneficiaries of the international campaign are patients. However, we encourage everyone who has an interest in nerve pain diseases to join the campaign. The list of alliances can be found on the [NERVEember](#) website. We encourage patient groups to organize awareness raising events and to coordinate their actions formally with iPAIN, whenever possible.

Patients and patient advocates use their voice to bring about change that:

- Achieves better and timelier access to quality treatment as well as earlier and better diagnosis of nerve pain diseases.
- Ensures that politicians continuously and increasingly acknowledge nerve pain diseases as a public health policy priority at both national and international levels.
- Helps to reduce isolation felt by people living with a nerve pain disease and their families.
- Increases and improves nerve pain disease research and orphan drug development.
- NERVEember amplifies the voice of nerve pain disease patients so that it is heard all over the world
- Supports the development and implementation of the US national pain strategy and policies for nerve pain diseases in a number of countries.

The Role of IPAIN:

IPAIN has a **guiding role** in NERVEember as the only registered owner of the project with an official trademark license.

IPAIN coordinates NERVEember internationally by developing common communication and awareness-raising tools which are made available on the [international website](#). IPAIN also oversees Friends of NERVEember, NERVEember logo and graphics, poster and image, the NERVEember website (www.nervember.org), NERVEember social media: [Facebook](#), [Twitter](#), [YouTube](#), [Instagram](#), [Pinterest](#), [LinkedIn](#), [Google+](#), and the [on-line news](#) service.

- IPAIN hosts an annual **events** and manages **press relations** in order to raise awareness and move forward key policies and initiatives benefiting people living a nerve pain disease.
- IPAIN **collects** and **disseminates patient stories, photos** and **videos** from the community and sends **regular updates** about the NERVEember project to the nerve pain disease community.
- We also **gather** and **evaluate data** on the results of NERVEember in order to report back on the global campaign efforts.

NERVEember is flexible but there are a few basic rules:

- Depending on individual and national community input, project partners and/or patient groups and other participants can choose to organize NERVEember around one single day, one weekend, several days, or a week or the entire month of November.
- Project partners may take the opportunity to collect funds or convince sponsors to support their actions, if 50% or more of the profits are donated to the iPAIN Foundation. All fundraising efforts must be reported prior to Oct. 15th for approval.
- NERVEember should not serve to promote any specific commercial interest and no visibility should be given to specific products.
- Project partners must avoid manipulation of the campaign for private interests. All events and actions must be reported.

NERVEember® 2016 Official Partners & Participating Support Groups



- Measures are being taken to prevent people using NERVEember for commercial purposes or to promote an issue which is incompatible with this patient-driven awareness raising campaign.
- The following disclaimer can be found in the Downloads & Materials, Get Involved and About this project section of the website: "The NERVEember logo is a registered trademark, not to be used for commercial purposes. The logo may only be used in support of activities organized commemorating and/or promoting the NERVEember project by iPain Foundation and in conjunction with our project partners. The logo, if used, should stand alone. Do not alter the logo in any way such as by changing the design, colors or the proportions, or crop it or combine it within any other logo. In case it is not possible to use the correct colors due to technical limitations, use the logo in black and white. A non-compliant use of the logo constitutes an infringement of IPAIN' trademark rights. Legal action may be taken to recoup any and all financial and promotional damages."

Project Partners

- **Use the common communication provided by the NERVEember committee and develop their own tools** to raise awareness of your AWARENESS event(s)
- **Collect patient stories** for media
- **Partners** should make or solicit video or written messages of support.
- **Gather** results of your efforts in order to report back to iPain on the campaign reach.

Planning Your Awareness Campaign

IPAIN is preparing...get your details listed at www.nervember.org, just send the who, what, when, where and why to ken@internationalpain.org

Materials you can use

IPAIN is preparing...check www.nervember.org for updates

Logos and Graphics you can use

IPAIN is preparing...check www.nervember.org



#NERVEember



NERVEember® 2016 Official Partners & Participating Support Groups



Video

IPAIN is preparing a two-minute promotional video for NERVEember 2016. The video will seek to promote key information about nerve pain diseases and convey the idea behind this year's slogan *"Join us in making the voices of nerve pain diseases heard"* as well as focusing on the 'Special Moments of HOPE' in the lives of people living with a nerve pain diseases. The video will be filmed using real patients. It will be patient-led and patient focused.

The video will not seek to promote any one nerve pain disease or organization but refers to NERVEember, the date, the theme and the website. All project partners and patient groups involved in the production will be acknowledged.

There will be a teaser of the video released near the start of the campaign and the full version of the video will be posted on the iPain [YouTube](#) channel and will appear on the NERVEember [website](#) in the weeks leading up to November 2016.

A link to the video will be sent via email to nerve pain disease patient groups through participating partners and country organizers during the project campaign.

The video will also be featured in the IPAIN weekly newsletter [Motivations](#) and will be sent to [project partners of NERVEember](#) page and everyone who subscribes to the iPain mailing list. It will also be promoted via the NERVEember [Facebook](#) page, [Twitter](#) page, [Instagram](#), and [Pinterest](#). Everyone will be encouraged to send the video to a friend and thus contribute to the viral success of the video campaign! The video can also be used by local NERVEember event organizers to introduce their events and to attract media attention.

Banner

A graphic for the 2016 campaign will be developed for use on your own online and printed resources to include your partner name. We encourage you to use it in your website and email signature during the month of November. Check www.nerveember.com for graphics.

