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### IG Therapy Ports

#### The Pros and Cons of Ports

By Abbie Cornett  
(Reprinted with permission from IG Living)

*Ports can be controversial due to the danger they pose for immune deficient patients, but in some cases, they may be warranted.*

September 2015

Great news for patients in California! AB 339, which will impact 14 million lives covered by commercial health plans if signed into law, is on Governor Brown's desk! The bill addresses specialty tiers and high out-of-pocket costs which has been the NAF's number one policy priority for years. AB 339 does the following:

- Establishes caps of \$250 per month for prescription drugs.
- Caps deductibles at \$500 for most plans.
- Prohibits health plans from moving a drug from a lower tier to a higher tier.
- Prohibits health plans from having more than four tiers.
- References federal guidance which prohibits discriminating against patients who are prescribed expensive medications.

Special thanks to all of you that have supported the numerous bills in California on this topic over the years. This historic

IMMUNE DEFICIENT PATIENTS and others who are treated with immune globulin (IG) receive this therapy in one of two ways: intravenously or subcutaneously. IV infusions can be from temporary peripheral IVs (the type typically performed when the IV catheter is inserted at each visit and removed after use) or permanent central lines.

A Picc line is a type of temporary central line inserted through a peripheral vein and may be used for several days and up to several weeks when properly maintained. Another temporary central line is a larger catheter venous line inserted directly into a large vein under the collarbone or in the neck and placed all the way to the heart. This type of central line and the Picc line can be inserted at the bedside.

There are two types of permanent central lines, both of which are surgically implanted. One is a large catheter that exits the skin with the end of the catheter available to access for taking blood or administering IV medications. The other, also surgically placed, is a port.

Traditionally, IG therapy is begun intravenously (IVIG), and if difficulty is experienced with accessing the vein, subcutaneous IG (SCIG) infusions are often recommended. More recently, though, immunologists recommend beginning SCIG from the onset of therapy. In some instances, instead of SCIG, there is an option of having a port installed, which can be controversial. Patients considering a port should be familiar with its advantages and downsides.

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## Sharing your Diagnosis

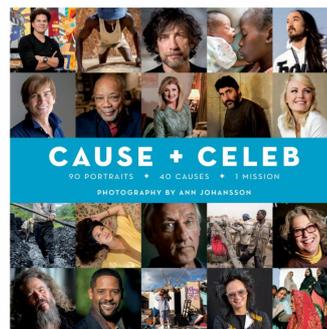
### Telling It All: How to Share the News of Your Diagnosis

legislation once again proves that one should "Never doubt that a small group of thoughtful, committed citizens can change the world; indeed, it's the only thing that ever has."

## Jerry Mathers & NAF

### Neuropathy and NAF Featured in "Cause + Celeb: 90 Portraits + 40 Causes + 1 Mission"

A book titled "Cause + Celeb" by Ann Johansson was recently released and it features Jerry Mathers and the NAF! Ann has spent 20 years working as a photojournalist covering news-related stories all over the world. During this time Ann has also had the opportunity to photograph celebrities from many different fields. Cause + Celeb is Ann's way of using her celebrity portraits to increase awareness about different ways of giving back.



Actors, artist, entrepreneurs, explorers and chefs among others offer information about organizations that they quite often have a personal reason for highlighting.

One of the celebrities featured is Jerry Mathers, American television, film, and stage actor, best known for his role in the television series Leave It to Beaver, in which he played "Beaver" Cleaver." The focus of Jerry's celebrity charity work is diabetes and the related ailment known as neuropathy. Jerry's cause of choice is the NAF! It is our sincerest hope that Jerry's continued support of our community brings vast amounts of awareness to the most common disease most have never heard of. The NAF is ever so grateful to Jerry for his ongoing support of the NAF and the neuropathy community. For more information on Cause + Celeb please visit: <http://causeandceleb.com>

### Diabetic Peripheral Neuropathy PSA Featuring Jerry Mathers Airs in 19 States Since June

In June the NAF re-launched a Public Service Announcement (PSA) focusing on diabetic peripheral neuropathy (DPN) featuring celebrity Jerry Mathers, from hit sitcom Leave it to Beaver. The NAF joined together with the American Podiatric Medical Association (APMA) in 2012 to create the PSA.

Neuropathy means "disease of the nerves" and causes tingling or numbness in certain areas of the body, especially the hands and feet. Diabetes is one of the most common causes of peripheral neuropathy, but knowing the signs and symptoms, and seeking expert medical attention from a podiatrist when the feet are affected, can alleviate the pain and/or numbness associated with neuropathy.

Jerry Mathers explains in the video that he has been diagnosed with DPN, but proactively monitoring blood glucose levels, following medication therapies, and seeking care by a podiatrist



condition might also be a therapeutic approach to processing your diagnosis and living with your illness. Below are some tools to consider when sharing your diagnosis with those who are part of your life and with the larger community.

#### *Stay Centered*

Staying centered works on two levels. The first is to share your diagnosis with others by placing yourself at the center of the process and envisioning working your way out. On a piece of paper, mark yourself at the center. Then draw consecutive rings around you. Each ring represents a different group of people in your life that you want to tell. Loved ones will most likely be in the ring that's closest to the center. Close friends might be in the next ring. Distant family members might be in a ring that's farther from the center. Add enough rings to represent everyone you want to talk with about your condition, and make sure their proximity represents how close they are to you. Now you have a guide for working your way out from the center. Depending on your situation, you might have to make some adjustments in terms of the order in which you share your news, but the diagram gives you a basic blueprint to work from.

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conditions that could potentially qualify for disability benefits. The Blue Book also describes which symptoms or test results must be present for an applicant to be approved. Neuropathy is listed in the Blue Book. The listing requires that you experience extreme occurrences of one of the following:

- Tremors
- Paralysis
- Partial paralysis
- Or involuntary movement in two extremities that makes walking or using your hands difficult.

If you do not meet experience one of these symptoms, you could still qualify for disability benefits. You can do this by having your doctor fill out a residual functional capacity (RFC) evaluation. An RFC will go through all of your symptoms caused by neuropathy, and how they limit you from performing all the work you would otherwise be qualified for.

#### *How do I Apply for Benefits?*

If you wish to apply for benefits, your first stop should always be the SSA's website. It will give you all of the information you'll need to apply. Birth certificates, work history, and your household income are just a few of the materials you'll need to apply. When filling out the application, be sure to write down as many details about your neuropathy as possible. The more meticulous you are, the higher your chances are for getting approved.

If you are applying for SSDI benefits, you can complete the entire application online. If you are applying for SSI benefits on the other hand, you will need to complete the application in person at your local SSA office. The SSA has offices in every state.

If you are denied benefits, do not lose hope! Nearly 70% of applicants are initially denied, but there is a hearty appeals process available for you. The first step of the appeals process is filing for reconsideration, which consists of submitting a simple form online asking for the SSA to evaluate your claim again. If this is denied, you can present your case in front of a judge at what's called an ALJ hearing. If the judge denies your claim, you can appeal that decision. Finally, you can take the claim to federal court.

With good medical documentation and careful note taking, your claim will hopefully be approved quickly!

### **Neuropathy Action Foundation**

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